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ABSTRACT

This report describes a qualitative study of the experiences and perceptions of parents of children with severe acquired brain injury (ABI) and summarizes the experiences of several parents during the first year following their child's traumatic brain injury. Twenty-five parents participated in a day-long focus group, in lengthy structured interviews, or in a stress management class. All of the children or young adults with ABI required intensive educational support services. Children's ages ranged from 3 to 40 at the time of data collection. A "meta-theme" arising from the parent groups and interviews was that the human tragedy of the permanent damage of a child takes place in the context of social institutions that are only minimally cognizant of the social and emotional impacts of the trauma on the family. Narrative and quotes are used to report parents' reactions concerning: (1) the time of the accident; (2) the coma experience; (3) efforts to maintain their relationship with the comatose child; (4) the rehabilitation phase; (5) coping with personality changes and behavior problems; (6) social isolation due to being away from school for extended periods of time and due to being placed in special education programs; (7) concerns about siblings; (8) financial worries; (9) helpful formal and informal supports; and (10) parental commitment and coping. (DB)

"You Can't Imagine Unless You've Been There Yourself" A Report on the Concerns of Parents of Children with Acquired brain injury

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A relatively new and growing population of children and youth has entered the public school and community service systems for persons with severe handicaps: children and youth with acquired brain injury (ABI). The discovery and dissemination of new medical practices has reduced mortality rates for people who experience severe head trauma (Sachs, 1991) The use of improved emergency procedures such as emergency medications which prevent brain swelling immediately following accidents, as well as the increased availability of pediatric intensive care facilities have contributed to these outcomes. Children and youth with the most severe trauma experience a period of time when they are comatose and require intensive medical care. After emerging from coma these individuals require intensive rehabilitation efforts to try to reestablish as many skills and functions as possible. Severe acquired brain injury results in permanent disabilities. Because of the plasticity of the brain and the normal malleability of children's development, long term outcomes are not easy to predict. Children can continue to regain skills during at least the first year following coma. Subsequently, they can benefit from instructional and rehabilitation efforts. Nonetheless, for children who sustain the most severe injuries, life long supports are required to enable participation in school and community life. These children frequently experience serious cognitive challenges and often face other sensory and neuromotor challenges.

When a child or adolescent experiences a severe acquired brain injury, the family also experiences trauma and may also need, at least intermittently, special supports to promote normal family life (Florian, Katz, & Lahav, 1989). The life course of a family whose child experiences

ABI is somewhat different than that of a family of a child who is identified at birth or shortly thereafter as having a congenital disability. In the former case, the child experiences a sudden trauma that changes him or her from a normal child to a child with severe disabilities. The purpose of this report is to describe parental experience of a child's sudden traumatic brain injury so that professionals who work with these parents might have a better understanding of the difficult experiences parents have survived. It summarizes the stories of several parents who described their experiences during the first year following their child's injury. Because of space limitations, this report does not describe children's return to school or reintegration in community and family. The study used qualitative research methods in order to develop an insider's view of the experience (Bogden and Biklen, 1982) and also to try to make real to the reader the particular lived experiences of parents (Guba and Lincoln, 1989).

Method

Subjects

Twenty five parents of individuals with severe acquired brain injury (ABI) participated in this study. Subjects were recruited by local chapters of the National Head Injury Foundation and by staff of a rehabilitation hospital Ten parents participated in a day long focus group in which they were asked to recount their experiences surrounding their children's accidents or injuries. Ten parents participated in lengthy structured interviews in which they were asked to recall their child's injury and their means of coping with resultant difficulties. Questions emphasized the topics of stress, coping and social support. The focus group proceedings and the interviews were transcribed for analysis. An additional group of six parents participated in a stress management class in which parents were encouraged to recall their experiences surrounding their children's injuries. The first author collected field notes during this eight week group that met for a total of 16 hours. Ten of the subjects came from urban areas in the Northeastern United States and sixteen from the Pacific Northwest. Subjects included mothers and fathers, married and divorced parents. The time since their child's injury ranged from one year to ten years. All of the children and young adults with ABI required intensive educational support services. All had severe cognitive sequelae from their accidents. Children ranged in age from 3 years old to 40 years old at the time of data collection. All of the parents were English speaking, of Euroamerican descent.. The majority of parents were middle class; two were upper middle class professionals, and two were poor and relied upon public assistance

Data Collection and Coding

Data was collected in group and individual settings. The authors asked a few general open ended questions (e.g. "Please tell us the story of what happened to your child and how if effected you.") followed by more specific probes (e.g. Who took care of your other children while you were in the hospital?). Parents were asked to describe what happened to their child and how they responded. In order to encourage parents to provide as much detail as possible in their answers, closed ended questions were asked to elicit detail about their thoughts and feelings in response to the situations that they described and the ways that they coped with extremely stressful circumstances. We asked parents to tell us about other people who were helpful to them in coping with a child's traumatic brain injury.

Transcriptions and field notes were coded for themes that emerged from a careful reading of the material as recommended by Glasser and Strauss (1967). Initially a large number of discrete code categories were developed. Subsequently, these were reduced by using superordinate themes that subsumed smaller discrete categories. Code categories were discussed by the authors in order to obtain agreement on how to label different portions of the transcript. We identified critical incidents and key excerpts that exemplify the major themes. In the presentation of results, we center each major concept around a quote from the transcripts. The summary that follows emphasizes those aspects of the experience of ABI in the family that were mentioned by a majority of parents.

Results

When parents of children with acquired brain injury talk about their experience, they organize it as life history that they divide into phases.

> ...the time of the accident, the occurrence, and what we had to face dealing with the immediacy of it and then the stresses that we faced returning home, in the community and currently.

The order to parental accounts derives from the major events and stages that unfold in the history of a severe head trauma: the accident, the period of coma, the period of intensive rehabilitation, the period of reintegration into the home and school. In presenting the themes that parents expressed in interviews and nominal conferences, we will preserve this order.

The time of the accident... what we had to face with the immediacy of it.

Parents remember the events surrounding their child's trauma in the vivid detail that characterizes our most powerful life experiences. They remember where and when they learned of the accident and communicate a sense that they were instantly plunged into a new and dire dimension of life.

> My son Patrick called and just from the tone of his voice I knew something dreadful had happened. I knew the minute I heard his voice it was just like a zombie talking. No change of inflection, 'Mother there's been an accident. Peter's been hurt.'

> ... I came on to the accident scene and immediately recognized my boy's bike in a crumpled state and that was, you know then went into auto drive. Everything went on automatic at that point.

Involvement with the emergency medical system began very soon after the accident for most parents. Depending on where they lived, most had to deal with emergency transportation. Distressing encounters with the medical system began immediately. Parents felt shunted aside.

> A lot of damage is done to parents before their children are in the hospital. These EMT's, the ambulance crews, the fire rescue people, need to understand that not only is the person lying on the ground or in the water injured, but so are those parents, and they need to be taken into consideration immediately.

Themes emerged in the different accounts of these confrontations: separation and isolation from the injured child, a lack of recognition of the parent's need for comfort and information, the need to make vital decisions under great pressure, a need for extraordinary efforts and endurance, and a fight against hopelessness.

> We had been told nothing. All I knew was my son was bleeding from the head skull. Scalp injuries bleed tremendously anyway. I had no concept of what we were looking at. I stayed with him. I spent 57

> hours in care with this kid. He was released to me 24 hours post-op and I was supposed to handle this? I was scared to death.

Several parents heard very negative prognoses at this point.

> That first night it happened I that, that really was stressful. They called me up here at like one o'clock in the morning and asked me if ah, I was his dad and I said yeah. And they said well, there was an accident and I said well how bad was it? They said 'he's not dead yet'.

Another mother was told of the severity of her son's accident at work:

> They said he was not a candidate for survival.

There was a strong sense of events being out of control.

> You start to learn about the fact that you can't control a lot of things but, like when you've had a good life, and you've had a good marriage and you've lived in this garden and watched life grow beautifully why you tend to forget these tidal waves that can overwhelm human beings.

Under these conditions of extraordinary stress, parents often were required to make major decisions quickly and with little information or assistance. In retrospect they wished they had some help with these decisions:

> ...from the very beginning, to have someone who is very knowledgeable about head injury to help you because there are a lot of decisions that have to be made right from day one.

When children were initially received by small hospitals they needed to be transferred to larger care centers. Parents were sometimes asked to chose the hospital but were given little or no information about alternatives. One parent reported being asked to select a neurologist without any prior information about the choices.

The time surrounding the initial accident also had a strong impact on the rest of the family. Several parents reported that extended family members helped out during the first days after the accident. Family members provided practical help such as watching siblings who were left at home and taking care of the house. Others stayed in the hospital to keep the parent company. During the emergency room and ICU period, some parents noted that friends provided relief during this crisis time.

The crisis also swirled around the siblings of the injured child. Often brothers and sisters needed to be cared for by relatives and had little idea of what was happening. In looking back some parents were concerned that the accident and subsequent separation from parents was also a trauma for siblings:

> ...his emotions have been on a roller coaster near all the time now so I don't know if that's related to the accident or not. I think it had to have been traumatic for him cause, you know, at the scene of the accident, I mean, he was literally handed to a friend and didn't see either my wife or I for over a week. You know, not knowing where, where his mom and dad were at when he was four years old...

The disruptions in family life were often extensive. Normal schedules and routines were set aside, sleeping and eating patterns altered, and usual patterns of communication distorted by the enormity of parent's emotional reactions.

Parents had very mixed reports about the quality of the emergency medical care that their children received. Reports ranged from that of one parent who had high praise for the staff of a small rural hospital that treated his daughter to reports of alleged negligence and malpractice. Some parents had shocking stories to tell: a child left unchanged and uncleaned in a full body cast for four days, another whose wound was stitched in the emergency room without cleaning it, another parent believed an ambulance crew was responsible for his child's experiencing heart failure and subsequent brain damage on the way to the hospital. Thus for many parents the encounter with trauma care was the beginning of a very mixed and often conflicted relationship with the medical and related health professions that treat persons with ABI.. The next stage in this painful odyssey was the period of the child's coma.

Coma

All of the injured children and youth described in this study experienced coma following their injury. The comatose state lasted for periods ranging from a few days to several months. Several themes regarding the period around the coma emerged from the interviews: great uncertainty and lack of information, a struggle to maintain the personhood of the child, a struggle to maintain hope, the value of personal caregiving, and the emotional drama of recovery of consciousness.

During the time that the children were in deep coma, parents struggled with preserving both the personhood of their loved one as well as hope for survival and recovery. When their children did not respond in anyway to the environment, parents had little to go on other than hope. Physicians often either communicated negative prognoses or admitted that outcomes were completely unpredictable.

> Peter had three major systems breakdowns and you see he had to be fed through tubes. I mean when you're in a coma a month why, I

> mean your body is really thrown into low and eight days after the accident, why they wanted me to take him off of life support ...
>
> They just didn't know...he was in a coma for like six weeks and in intensive care for six weeks. And, we never knew and the doctors couldn't give us any hope. They just didn't know. They'd keep telling us well, we got to wait till the swelling goes out of his brain before we know what to expect.

For some parents negative prognoses at this phase were causes for both anger and pride and determination later on. The anger was directed at the doctors for not having hope. The pride was for their children's unexpected recovery, and determination to continue trying to obtain improvements even in the phase of negative predictions.

> I have survived, and I'm pushing for more, because every doctor I have spoken with told me, 'Your son will never come out of a coma, and if he does he will be a vegetable.' Vegetable now is growing flowers and doing well.

One mother described her wish that the neurosurgeon would have been more direct in communicating some hope.

> We knew it was serious. We didn't need a doctor to say that. What we needed to hear is there's always hope but it's very serious. I mean, and it's, you know, what is it? Six or seven words. And I don't think they have to be able to do any more than that. Perhaps shake your hand or hold it, look you straight in the eye and say 'This is very serious. But there's always hope.' But you see, that wasn't given to us at all.

I just had to have someone seeing my son as a real special human being.

The children lay in hospital beds and often were hooked up to tubes and equipment. They were changed, sponged off, and tested by nurses and physicians but did not interact or respond to any of these caregiving efforts. In this circumstance, it was important to parents to maintain relationship with their children as persons; that is, as people with thoughts and feelings, a personal history, preferences and wishes even though there was no visible evidence of any of these personal conditions still existing. At the same time, parents still felt shocked and frightened.

> He was really out of it you know, tubes at his head and a sack gathering up brain fluid, so you know, and, and he looked so bad he just looked so bad. That that was really frightening. Scared me.

Parents tried hard to maintain a relationship with their comatose children by talking to them and touching them as if they were responsive. Efforts to communicate were both aimed at trying to elicit recovery as well as to maintain person to person close emotional contact.

> We would go in and work with him. We'd take a key and rub on the bottom of his foot when he was in intensive care to see if there was any reaction whatsoever. And it was quite a thrill the day that ah, we saw him move his toes.

> I couldn't bear the thought of my son laying in intensive care with people that didn't know him, didn't care about him except as a body that they were responsible for. They didn't notice this gift. And so I collected photographs from different places. From the time he was in preschool, well from the time he was a baby. And I put that in his room in the intensive care unit. And I wanted so for him to become a person to somebody. I knew that it wouldn't effect certain people but then for others that key to a visual image... It was because I just had to have someone seeing my son as a real special human being.

Some parents felt that in the effort to save their child's life the medical staff lost sight of their child's individuality and also of the parent's emotional pain. With some exceptions in which parents believed they received substandard medical care, they felt that the hospital did a better job of taking care of the patient's physical needs than of the child's and parent's psychological needs.

> Well, of course, I want you to fight for his life. You know, I don't want one centimeter of effort lost in his behalf. But I think that professionally they certainly did their job. Psychologically, no. I mean it was incredible.

Many parents were critical of the lack of concern they encountered from some professionals. Complaints about professional communications centered on two areas: lack of knowledge about head injury and lack of concern about what parents and family members were experiencing.

> Do you know that in the early stages when it was getting towards the point where our daughter was returning home, that the insurance company had us visit a psychiatrist. It was a total waste. I could have told that girl things. She didn't know beans.
>
> I saw the neurosurgeon. I didn't see the man for a week (after his daughter's surgery) and he says, 'I suppose you would like to talk to me.' Prior to that he said,' If I have anything else to tell you I will tell you.'

When asked about who was supportive of them during this period, several parents mentioned nurses who were helpful. Some parents mentioned having favorite nurses. Others said that the nurses gave them much more information than the doctors. One parent described how a nurse taught him how to care for his son by washing him and that being able to help with this kind of personal care was very important. One parent complained that the hospital rotated a favorite nurse to different duties and thus terminated an important relationship.

The coma and intensive care phase often lasted for weeks. Parents had to cope with finding care for children at home, dealing with jobs and the other normal demands of life that had to be set aside for this crisis. Parents whose children were moved to centers far from home had to find places to stay near the hospital or commute for long distances. During this period of protracted intensive care some parents began to experience the first tastes of social isolation which later became a major concern.

> It's like you're an island. You're isolated. People don't want to step in to these situations. I mean, I think that the level of pain is so great and everybody has so much pain already, so many troubles of their own to deal with that you tend to be shunned from the very beginning.

Other parents continued to have the help of friends or relatives during this time and they remembered it with appreciation.

The emergence from deep coma and gradual return of skills marked a new time for parents. Most had little idea what to expect. One parent said that all he knew about coma was from watching television and he thought that when a person emerged from unconsciousness, that she would wake up and have her full faculties. He also assumed that progress would be steady and without setbacks. When the course of recovery was very gradual with many ups and downs, this parent was bewildered. Each step forward represented hope of the child returning to normal and each step back raised the fear of the child regressing back into coma or failing to recover. Once again parents were not given information about stages of recovery from coma.

Every parent had a vivid memory of moments when they first were able to reestablish communication with their comatose child. In retrospect these occasions were very important to them and were remembered with feelings of joy and gratitude.

> ... a thrill when we'd say, 'Darell, this is Dad. Do you hear me? If you do, squeeze my hand.' And he'd squeeze, you'd feel his little squeeze in the hand.

> Initially it was really tough because we was unresponsive. And then when he responded uh, it was the fourth or fifth day, it really lifted our hearts. And then to be with him and watch him progress from originally not being able to communicate at all to at least being able to say something at the end of the four weeks. . . really did us some good.

> ...by the time he was able to talk to me there was I don't think any shadow of death left. But this would have been sometime during the... fourth or fifth week...that was a joyous, joyous, joyous time. And you know, Lord the smile. Oh, my. He was so glad to see me and I was so glad to see him. We just sat there and smiled like fools.

This experience of the reemergence of a loved one after going away into coma and hovering near death was a very powerful one. It often appeared to the parents to defy the negative predictions of the doctors and to similarly challenge the seemingly impersonal nature of hospital care. Thus in the parent's experience there was very strong emotional evidence that they had good reason to hope for their child to return to normal. This hope was reinforced by the gradual reacquisition of skills during the first year following the accident. For some parents it did not become clear to them that their child was forever changed for a long time after the accident. And they had strong experiential evidence to encourage them to believe that eventually any sequelae would lessen or disappear altogether. Again, in retrospect, parents wished that they had been given much more information about the long term impact of severe head injury. In particular, they wished that they had been informed about the changes in social behavior and personality that are usually associated with severe ABI.

Rehabilitation phase.

Most of the children studied required several months of intensive rehabilitation before they were able to re-enter their homes and school systems and return to a semblance of a normal daily schedule.

After recovery from coma children were either transferred to rehabilitation hospitals, or in areas with no services, were sent home. In the rehab units, parents learned that the professionals had a different focus in working their child. The emphasis shifted from biological survival to the recovery of previous mental and physical status. And in this phase the child had to be much more of an active participant and ally. When it was time for children to enter rehabilitation, some parents first encountered the scarcity of services for pediatric rehabilitation. Some parents had to bring their children home and manage the rehabilitation the best they could. Others believed in retrospect that the rehabilitation program that their child received was not really designed for children but, instead, that staff had primarily had experience with adult head injury victims whose needs were different. Other parents had to send their children far away from their home community for rehabilitation. One sold her home and moved to the city where services were available.

Once again parents recall the rehabilitation phase as all absorbing. Normal family routines and schedules as well as social interactions were disrupted as parents either spent a lot of time in the hospital or devoted a great deal of time to the child's rehabilitation at home. Several parents described the need to commit large amounts of their time and energy to helping their child to recover. For many these efforts were exhausting. For the most seriously injured children, the demands of caregiving continued from the rehabilitation phase up to the present. Exhaustion began to take a toll during the year following the injury. Caregiving demands in addition to being tiring were also isolating.

> My wife gets up at 5:00. She has a difficult time a lot of days to find time to go to the bathroom or eat. Many nights my wife doesn't eat because she is doing the laundry... and she sleeps in the same room with my (brain-injured) daughter. There is nothing like going to any social meetings. We don't have time for that kind of stuff. Geez, I don't know where anybody finds time to do that.

Parents wanted to believe that absolutely everything possible that could be done for their child's recovery, was done. It appeared that it would be unacceptable to parents to believe that less that 100% of the possible was attempted. Given the limitations available in rehabilitation services and their tremendous costs, this meant that a major amount of rehabilitation and caregiving work fell to the parents and that they held themselves to very high standards of what they must provide.

> ...I always said, well, my biggest problem always during this year of intense effort, it's sweat. Oh, God he works so hard. By lifting weights you know, with his hand and on his ankles and sitting on a big ball trying to keep his balance and I went out and bought him the sturdiest bicycle I could find because I didn't want those leg muscles to atrophy while he couldn't walk.

This parent's son cooperated in the rehabilitation efforts. Anything he was given to do, he worked hard to accomplish. Except that he refused to go outside of the house. He was still unable to communicate fully and his mother was unable to understand his resistance.

> And I finally reached that point where he could give me enough of an answer. He didn't want to go outdoors until he was all well. And I realized that there had to be a great push made to break that...(his decision that)...if he was going to be outdoors he had to be 100% well. And so I got him a puppy for Christmas and he had to walk his dog. That was the only negative I saw in Peter...was that he didn't want to go outside until he was all well.

Often these efforts entailed a high personal cost; they had an impact on relationships within the family, social ties outside of the family, and the fiscal status of the family. Some parents reported that they did begin to learn to balance their own needs with their child's.

> I think some of us learned that from the hospital...or from some support person who got to us who said, 'You got to take care of yourself.' You know, or my husband and I would have never realized that we needed sleep or we had to eat, you know.

But others found their child's needs so compelling that, in retrospect, they felt that relationships with spouses and other children suffered.

> I think the first thing that came to mind on my list (when asked about stressors) was the family relationships and how do Brendon (spouse) and I cope with the stress that occurs between us because of the injury.
>
> It's just that we are always so busy. There is no time for a relationship between us, and we are the foundation for our family.

In some couples, the accident and subsequent caregiving strained the marriage to the breaking point.

> My husband insisted on her (daughter with head injury) going home because there was no place except for a place in Jersey where they wanted to just put her away and forget about her, and my husband insisted on her coming back...after about three months, my husband left, he couldn't cope with it anymore...
>
> My son was hit by a car eight years ago. He has spent about four months in ICU (intensive care unit for coma) and then he went to Sunnyview (rehabilitation hospital) for another four months. I just think that this accident ruined our lives completely because my husband couldn't cope with it. I didn't have any help...we went to all the counseling, and it still didn't save the family.
>
> We are here (at the focus group) because we survived. I know a person in (our) situation who cannot cope at all, who can't do it, and how many husbands or wives have walked out and have washed their hands?

Coping with the accident and its aftermath did not break up every marriage. On the contrary, some parents reported that it brought them closer together. Another couple described the accident as both bringing them together and also causing more occasions for arguments.

> I think that initially it brought my wife and I closer together but then it probably pulled us apart. It gives us more instances to disagree... how we should proceed with Dennis and do things over dealing with our other children...I think that had we not been where we were, it might have torn us apart...We knew we had to hold together, that to survive with the family.

Coping with personality changes and behavior problems

One of the most divisive issues in some families centered around the injured child's problem behaviors after the accident. Closed head injury often involves trauma parts of the brain that are critical elements in the generation of behavior that we normally think of making up personality. ABI victims commonly experience difficulties with social judgement, normal affective behavior, and impulse control. After the child has returned home and his rehabilitation process has been underway, these social and behavioral challenges emerge for many parents as the one of the most difficult legacies of the trauma. Some of the personality changes were relatively benign:

> Dennis was somewhat quiet and introverted before the accident and he's very outgoing and extroverted now...he's not afraid to go walk up and give someone a big hug. You know, for an eleven year old boy to do that now, you know, that's not cool. Dennis doesn't even think about it. He goes, if he wants to give somebody a hug, he does it.

> It isn't that the symptoms are different. It's that the controls aren't there. For instance, I can remember with Brendon; he always had a hot temper but before the accident he was cool. After the accident it hit the fan. All those controls were gone. His main problem was

> ah, he was still 17 years old and he thought he was very popular with the girls and he'd try to make out with the girls and he'd try to make out with every girl he saw.
>
> (Before the accident) He just didn't talk much and he was always very close to his mother when he was growing up and , then after he started talking, come out of the coma and started to talk, he never shut up. He just talk, talk, talk. And a stranger, he didn't know what a stranger was. And he just aoout talked us to death (laughter).

The problem of disinhibition, a loss of normal constraints on emotional reactions, was much more serious for some parents. It was particularly difficult when the impulsive behavior involved anger and aggression.

> I went to him (14 year old boy with ABI) and said, 'Son, what have I done to make you so angry? I have tried so hard to stand beside you, in front of you, with you. Why do you hate me now? What have I done? Can I fix it?

Parents reported that the onset of behavior problems took them by surprise. Again they wished in retrospect that they had been given more information about the probability of behavior problems and personality change associated with ABI.

> Is it possible that this head trauma, this behavior, is a direct result of this trauma? Is there a guideline to what head trauma kids go through? You have a progress with almost any disease.

When these problems first emerged, parents and professionals did not attribute them to brain injury and, in some cases, the children were given inappropriate kinds of treatment.

> Like I said, we anticipated physiological problems. We did not anticipate what appeared to be psychiatric problems. ...my husband

> and I went through a crisis of our own questioning alcohol and drugs (whether or not the injured adolescent had a drug problem)...and we ended up forcing him to voluntarily commit himself. Had we realized, had we known...we could have taken the appropriate measures then, taken him to who he needed to see instead of putting him through 60 days in a private psychiatric hospital where he was subjected to (people who experienced) alcohol abuse, drug abuse, suicides, homicides, personal mutilation, all of the things that I --- when they were born, I never wanted them to see.

It is important to note that not every child experienced serious behavior problems and that, in some cases, the kinds of personality changes that occurred were viewed as positive. For example, two parents talked with admiration at the way their children continued to work to recover from the injury and to face challenges posed by their altered abilities.

> I live on a day-to-day basis. I feel she is doing super. She is a very positive, patient kid. No fear. And one thing we can't compare today what Kelly is like to her first fourteen years except she has not lost her determination and we go day-by-day and each day we learn to accept what we have to accept, but I'm not done and she is not either.

In our interviews with parents of young adults with head injury, we found that some parents were still very concerned about social and behavioral problems several years after the injury. One father described his irritation at his son's temper and argumentativeness. Another described continuing embarrassment at the way his son, now an adult, would approach strangers and strike up conversations that were inappropriate.

In some cases behavior problems were cause for dissension within the family. In cases of anger and aggression, the child's problem behavior raised interpersonal tension among other family members.

> It almost got to the point of domestic violence.. We were so frustrated, and he was violent, and we had no support.

In other instances, family members became divided over their view of the problem behaviors. In one such family, the mother attributed her son's difficult behavior to his injured brain and assumed that it was out of his control. As a result, she viewed him as essentially blameless. On the other hand, her husband had the view that moral behavior was always under a person's control regardless of brain injury.

> And I told him, I says Sean, you know, you know in your mind what's right and what's wrong. And some of the stuff you pull is wrong. And you know it's wrong. Don't do it. But he just, he just won't listen.

Siblings in this family were also divided in their opinions; one sympathizing with the brain injured brother, the other blaming him for acting in problematic ways.

> ...his brother George, he's the oldest...gets along real good, cause George was always the bad boy in the family...Now my second boy, he won't have nothing to do with Sean. He bugs, Sean bugs the hell out of him and he won't have nothing to do (with him).

Changes in the child's personality pose one of the larger challenges for parents in their longterm process of adapting to the effects of acquired brain injury on their child, themselves, and their family. Parents described how this process involved both coping with the loss of the child as he used to be before the accident and accepting a new, changed person.

You Can't Imagine

Parental experience in coping with a brain injured child involves a simultaneous process of grief and adjustment. For many parents, even years after the accident, there were times of strongly felt sorrow as if a child had died. At the same time, they needed to relate to the changed child. The mixture of emotions was somewhat confusing and, as with many aspects of their experience, parents felt that other people could not easily understand this mixture of thoughts and feelings.

> I mean it was like schizophrenia. I'm looking at this kid who looks the same. A little bit of balance problem, a little deficiencies, but this is not the same kid. I'm going crazy. My husband is going 'You're fine.' My mother-in-law is going 'You're psychotic.' I needed to have someone who I felt was solid, someone trusting, a professional someone who has the education to tell me, 'Yes, Ruth, it is fine. Tear your house apart. Scream and yell and mourn this child.'

This process of mourning for loss of abilities and accepting a changed person also happened for many of the injured children. That is, they remembered themselves prior to the injury and have to come to terms with their own loss.

> The crucial thing is that the child himself knows he is different. If you can't accept the new kid, the new kid can't accept himself. He is fighting you every day.

Some parents expressed bewilderment about what to say to their child about the loss of abilities.

For some parents the accident and loss of their child-as-known-before occasions a loss of meaning. One father spoke bitterly about his loss of faith in God.

You Can't Imagine

> Do you believe in God all of you? Did you ask and you receive? Did you ask to receive a brain-injured child?

Another mother described, almost poetically, the way in which the accident not only raised grief about loss of the son she had and hoped for but also how it brought to the forefront other feelings of being cast-out by the benevolent side of life.

> I no longer believe that if you work at life it lets you walk off into a beautiful sunset. So where does that leave me? Still trying but not really believing? Off the track permanently? Yes, there is a God and his purpose but my faith is an imperfect vehicle... My former identities as a wife and mother, I'm sorry, have eroded and disappeared in a cloud of dust leaving nothing in me that is coherent.

Some of the parents also described a period of time in which they experienced guilt and anger. One parent mentioned the fact that she had bought the bicycle that her son was riding when he had his accident as if she might have prevented it if she had not purchased the bike. Others expressed the worry that they were not doing enough for their child's rehabilitation.

> The guilt encompasses many, many things such as, "Am I doing enough? Could I have prevented this ABI?"

Parents expressed the wish that the professionals who worked with them would know how to counsel them about guilt and grief--or, be aware of their feelings. They felt that social workers, therapists, and counselors needed to be educated about the effect of head injury on parents.

> We need to get to our mental health people. ...(they) need to know that the minute they find out there is a head trauma injury involved undoubtedly the parent is going to feel guilty, that they are going to feel the definite mourning process because the moment that accident happens that child and their lives are changed permanently forever, completely...

Dealing with such strong emotions and pervasive feelings of doubt was a solitary struggle for most parents. Again and again they mentioned their difficulties in making themselves understood by others.

Social isolation , the communication of stigma and the creation of a handicapped identity.

An injured child's status is often unclear for a considerable length of time following a traumatic brain injury. Realization that the child is permanently changed as has a different identity as viewed by the world is communicated by some key events that happened after the child returns home and is returned to public school. During the period of time when parents were beginning to understand that their child was permanently changed, they were simultaneously receiving powerful messages from their social community.

> The biggest disappointment was later on when the friends and his friends... just kind of faded away from us.

Several parents discussed their perception that the accident and subsequent changes in the family's life resulted in social isolation for both parents and the injured child. Most parents indicated that family and friends were available during the immediate crisis following the accident and that their practical support was of critical importance.

> ...my husband's brother's wife had enough objectivity to deal with this...She was instrumental in getting someone to clean my house, someone to mow the lawn, someone to take care of our other kids.

Others described relatives or friends who visited the hospital while the child was in the ICU. One parent told of a good friend who would sit by the child's bedside at night so that she could get some sleep. The injured child's school friends were also active during this crisis time. However, after this initial period, supportive people began to withdraw. This process of withdrawal from the family and child communicated to parents that their child had a new identity, one that was devalued by the larger community.

> ...at the time he was in the hospital...we had several friends that came up to see us and to see Darell. I guess the biggest disappointment was later on when our friends and his friends found out that it was more of a permanent situation, then they just kind of faded away from us and, especially his friends. They just stopped coming around. Didn't see him any more and that was kind of heartbreaking.

The loss of school friends can be partly accounted for by the amount of time that the children miss in school. They often miss a full year of schooling so that their age mates have moved on to a new grade level upon their return. Also, the same kinds of physical and psychological changes that require parental acceptance intrude on friendships. For example, the father of an eleven year old whose son had become uninhibited about showing affection to peers since his brain injury described the effect these behaviors had on peer relations:

> You know, that isn't cool now for him to be doing that. He gets the peer pressure for that...

Other children were subjected to teasing because of their altered abilities.

> ...it's so awful to have people look at your child like he's stoned or drunk because he doesn't have good ...balance. I wouldn't care if he didn't have both of his legs. He's still the same person but it's awful the judgements that we lay on other people. You know, they have these crushing expectations.
>
> People make these assumptions. If you don't talk absolutely clearly why you're mentally retarded or else there's something wrong with you so that these quick assumptions we use to judge people by are continually working against anybody who is severely handicapped with head injury. And just because you may be slow in the way you speak or because you can't respond to questions quickly, people write you off.

Many of the children were aware of other's reaction to them. One parent described how she understood that her son was sensitive about other children's reactions to him upon returning to school from the hospital:

> I asked him once when he came home. I asked him why he watched the ground so much and he said, 'Well, I don't have to see the expressions on other peoples' faces when they look at me. That was the only inkling that I ever got of how he suffered from awareness.

Thus the loss of the child's friends and subsequent problems of teasing and rejection communicated a sense of social stigma that others assigned to a person with visible differences in abilities. The process of isolation for the parents appeared to be more complicated.

Initially, for some parents, the isolation began as a result of their total absorption in their child's care and recovery. It meant that they had little to talk about with other people besides their very strong feelings concerning the hospital, their child's health, and related concerns.

> I couldn't (wasn't able to socialize) after that accident. It was like I could live intensely in this loving world with my son. But if somebody came to visit and asked how are things going...I couldn't hardly cope with it...it was like I was somebody that was wound up like a toy and once I got started all this, this anger started coming out...and I was raised, you know, that's inappropriate behavior. You're not supposed to express your feelings like that. And I was appalled with the amount of emotion I was containing.

In the midst of feeling these overwhelming emotions, it was hard for parents to respond to other family members who were also grieving.

> ... you have your extended family who is there grieving also, and sometimes I think you want to say, 'What are you feeling sorry for yourself about? I'm the one in this situation.' You have to deal with their grief when you aren't even through dealing with your own grief, so sometimes it's even more-- it's harder to have them around depending on the relationship.

The problems in maintaining friendships were also related to the practical demands of caregiving. It was often difficult to get away in order to spend time with family or friends. One parent described the way that their many friends eventually stopped calling to invite him and his wife out because they were always too busy with caregiving after the accident. Finally, one theme that ran through the comments of most parents, was the way they felt that other people simply did not understand them. Partly, this sense of distance from others grew out of the well meaning but nonetheless fatuous comments that people would make. Several parents had examples of unhelpful help:

> ...and you get sick and tired of hearing 'I don't know how you people do it. How do you do it?' What (else) are you going to do?

Parents wished for more understanding from the people around them.

> If people were more aware of what you have got to go through every day of your life they might be a little bit more understanding. I don't think you would be as isolated if the awareness were a little bit more than what it is...if there was more awareness of everyone around you of exactly what you were going through, the isolation, the social relationships, the burnout, the fight.

Parents wished for this kind of understanding from both friends and relatives as well as from professionals. The process of returning the child to the public schools was also isolating in several cases. The children in this study were intellectually and physically normal prior to their injury. When they returned to the public schools after long periods of time in hospitals and rehabilitation programs, most of them no longer were able to be served in their previous classrooms. All of the children in this study were identified as requiring special education and were placed in programs for children with mental retardation. The process of placement thus entailed assigning children a new label and placing them on a new track in the public schools. For many parents this process of special education labeling and placement represented the first concrete statement from the broader community that their child had a new social status. Some parents felt that their head-injured child did not belong in the same program as mentally retarded children. Others felt that the school staff was unprepared to serve children with acquired brain injury. The complex needs of these children often outran staff skills. For example, one parent reported that her son needed to wear an arm and hand splint for an hour a day at school but that the staff kept putting it on incorrectly. Another parent reported that it was necessary for her to train the school staff in how to work with her daughter. She complained that the school's policy of rotating personnel from year to year meant that retraining of new staff would be necessary.

The tremendous variability in school services in different regions and communities was evident in parental reports about return to school. Although, some parents were distressed at the quality of school programming for their children, others were impressed with the range of services that were available:

> ...(school) has done as much for my daughter as any rehab hospital or anything else. They have licensed therapists, occupational and physical therapists... and the bus comes every morning.

Return to school not only marks a critical milestone in the community's redefinition of an injured child, it also represents a substantial disjunction between two service systems, the medical /rehabilitation system and the public school system. The former system is usually funded at much higher levels by private insurance. Therapies and treatments are delivered in one on one sessions with health personnel and services are viewed as part of medical treatment. Thus reintegration into public school usually follows a period of intensive rehabilitation work either at a hospital or at home. Upon re-entering public schools the children had to share staff time and resources with several others. In some cases, parents were disappointed in the way in which their child's physical and educational needs were not given as much care as previously.

> ..it turned out for us that we had to be constantly vigilant to make sure that his IEP is being followed.

Some parents were also disappointed in the way in which the schools were very slow to implement their children's instructional programs. They expected that the IEP would be implemented early in the school year. Once again, it seems likely that expectations are built up during the rehab experience in which children are given one-to-one assistance and programming and that these same standards cannot be readily met in a school setting where there are many more children and fewer resources.

Parents had other concerns about the way that teachers dealt with their children. One parent complained that the school staff was overprotective of his son. For example, they allowed him to nap regularly instead of requiring him to engage in classroom work. Similarly, parents had concerns about how other children treated their injured child and about behavior problems. Thus when children return to the public schools, parents are by no means finished with the job of monitoring and advocating for services nor does their child's adaptation to school necessarily settle into a predictable pattern.

Concerns about siblings.

Another set of social and emotional issues that parents described focus on the brothers and sisters of the injured child.

> My older boy had a lot of problems dealing with his brother, with the illness, with the trauma that he saw.

Acquired brain injury effects every member of the family. Several parents reported that uninjured siblings experienced difficulties as a result of the trauma. Some brothers and sisters developed behavior problems. Others had difficulty in sleeping or trouble at school. Parents attributed these problems to the trauma involved in seeing the accident, to the separation from parents during the hospitalization, and to loss of parental attention.

> ... my older boy, he was intact. In other words, alive, so I thought 'Well, I will have to deal with him later,' - months and months later I dealt with the problem.

Once again, parents desired information about the impact of head injury on other family members and on ways to cope with these effects. One wished he had :

> ...a checklist to say, 'Is this child in trouble? Do you see this, this and this happening?' Not to the injured child but to the surviving sibling. My daughter couldn't sleep. She had incredible sleeping problems...all kinds of things that we knew that she needed help.

Like their parents, brothers and sisters also struggled with feelings of guilt, loss and grief. One particularly poignant story illustrates these cognitive and emotional reactions that siblings can have and the need for someone to attend to them. One mother was away at the hospital for three and a half months while her daughter was in a coma. She tried to explain coma to the four year old and twelve year old brothers.

> We had to explain to both kids that Suzette was sleeping, and she was hurt. She had hit her head and she was hurt. When I first had gone home after three and a half months they had in school what they called a journal where the kids would keep a diary that nobody would ever read in school. And Billy had all the pages stapled closed. I opened it because I wanted to--he couldn't talk to anybody, and I wanted to know what he was feeling, and all he kept writing was, 'I wish it was me. It should have been me. It shouldn't have been my sister.'

Parents were also concerned about the role that siblings should play in caregiving. On the one hand, they wanted the brothers and sisters to be helpful. On the other, they did not want to unduly burden them with responsibilities that would be too burdensome. They also struggled to give enough time and attention to the nonhandicapped siblings and also assist their brain-injured child.

> It's a big one (problem)--making sure everybody gets their time, and not putting too much responsibility on the older kids, the more capable kids, in taking care of him (the injured child), though I trust my kids with him more than I trust any other stranger in the world.

Financial worries

In addition to the social and emotional impacts of caregiving on parents and siblings, the people we interviewed also had many practical concerns about finding and paying for appropriate services for their injured children. The costs of long term care and many inequities in the system of medical payment were a great concern.

With his medical bills alone, it's upwards of $15,000 that I am in debt.

Medical treatment from the emergency room, to intensive care during the coma, to rehabilitation and follow-up is very expensive. Several parents were faced with enormous debts.

> I have a lien on me. I have a loan of $450,000 from the New York State Department of Social Services for this kid. Where do you get this money?

Parents discover quickly that money is a key to obtaining services for their children. From the beginning doors either open or close for their injured child depending upon parental resources.

> The first thing the rehab play is, they take you in the board of director's room and sit you down at the table and they want to know if you have got insurance before they even take you. That's the first thing they want to know, and if you don't have insurance, they don't want you.

Those parents who had private insurance had complaints about difficulties in getting payments for items such as special equipment. Most insurance policies have time limited rehabilitation payments so that termination of rehabilitation services was often determined by the end of insurance payments rather than by the needs of the child. Other parents were faced with prohibitive increases in the costs of their health insurance once their child became a long-term patient.

Parents who were receiving public assistance had many difficulties in using Medicaid. They found that many doctors would not serve them because the Medicaid payments were too low or too difficult to obtain. Parents who required long term care for their children who did not recover from coma said it was difficult or impossible to find services and to pay for them. Thus these parents suffered from the lack of catastrophic health care insurance and restrictions in public assistance that characterize contemporary health care funding.

Parents had another set of concerns regarding public school services for their children.

What helps.

Up until this point, this study has emphasized the suffering and the frustrations that parents and other families members experienced in coping with the acquired brain injury of a child. There was, of course, another side to the picture. Parents did describe a number of formal and informal supports that were of genuine help. They also either described or showed us a variety of coping strategies that have been adaptive for them.

From the outset, parents had to rely on the competence and efficiency of medical personnel and systems for their child's survival. Several parents expressed appreciation for the way that local hospitals served their children. In almost every case, children were close to death after their injury and their lives depended upon the availability of emergency treatment and the skills of doctors, nurses, and technicians. These urgent services were rendered under the utmost time pressures and often in difficult circumstances. Parents were appreciative of them.

> They have done a fantastic job under the circumstances. I don't want to see my daughter hurt in the head, but they done a great job in my hospital.

In retrospect, some parents were able to forgive the poor communication skills and lack of interpersonal concern that so often seemed to characterize the people and the procedures in medical settings.

> I guess what I am saying is that they have been schooled many times, that they have to protect themselves with this shell, and that shell can hurt you, and you can still be coming off of anger for months and years later from it even though you are saying, 'Hey, it was good because they saved my son.'

When professionals were able to communicate with both clear information and empathy, parents were very appreciative. It was clear that parents desired both professional competence and human warmth--neither by itself would be sufficient.

> ...the nursing staff was great. They had set up in the pediatric emergency room or intensive care room, told all the shifts so we had the same nurse everyday for Dennis. Actually the same two nurses so we got to know them real well. They were very supportive. Carol (spouse) and they would talk about Dennis' condition and we actually got more information from the nurses than we did from the doctors.

Similarly, when parents had adequate insurance coverage and cooperation from the company, they reported being able to obtain services that made an important difference to their child and their family. One of the parents who had the most fiscal resources available through full insurance coverage was able to hire a personal casemanager to take care of the large volume of paper work that was generated by the many agencies and services that his child required. Another family was able to hire private duty nurses to help with the rehabilitation phase at home. Once again, if the personnel did not exhibit competence, merely having the resource was not sufficient. The combination of adequate resources, professionally competent personnel and good communication was appreciated in the rare instances in which it happened.

Several parents noted that professionals generally were not well informed about acquired brain injury and its aftermath. Many of them found it necessary to read and learn as much as possible about their child's condition; this sometimes put them in the position of being more knowledgeable than the 'experts'. When professional staff were willing to learn from well informed parents, both sides appeared to benefit. In addition, continuity of services and personnel was particularly important given the need for special knowledge of their children. A commonly expressed frustration was the frequent turnover of personnel ranging from from the ICU nurses to the special education teachers. When hospitals and schools established procedures that led to continuity of staff, parents were grateful.

Formal services and financial support were only a small part of the resources which appeared to make a real difference to families. Informal sources of care and companionship were at least as important. When it worked well, immediate and extended family were invaluable. When asked if there were any people who were very helpful during the hospitalization, one mother answered:

> Oh, yes. I mean, you know, what is greater than a family?

Parents reported that family members helped with practical concerns such as house care and child care for siblings as well as emotional support. Similarly, friends and work associates were also important to some parents. One parent described a friend who stayed with her son at night. Another talked about a church group that offered practical assistance as well as emotional solace. Some of the most helpful contact came from other parents of children with brain injuries.

> My son swims for a swimming team for the physically limited and one of the boys that is on the team is head injured and, we just met his mother Saturday and my wife talked to her about the common problems we have and seemed to hit something off.

It was essential to parents to make contact with other people who had believable experience with the conditions that they were suffering.

> I need somebody who has been through it or who has been through it with other people --that know what to look for, what problems to look for.

They also wanted contact from the time of the accident with someone who was knowledgeable about acquired brain injury and its treatment. They felt that they were left in the dark for long periods of time and had to make many important decisions in the absence of clear information.

> I felt that you definitely need somebody right there as soon as it happens that is knowledgeable and knows the ropes...

One parent was able to obtain both information and emotional support from a staff member of the local Head Injury Foundation and reported satisfaction with this help.

Respite care was also greatly valued. As described earlier, the long-term demands of home caregiving can be exhausting and can greatly limit a family's opportunities for normal activities. When parents and siblings were able to get a break, they usually enjoyed it. It was necessary to find someone who was trustworthy and competent to take care of the injured child while the family got a rest.

> We were in a position to have someone we hired to come in and stay at home so that our older boy would have care when we were away. This was invaluable to us.

Another kind of personal assistance that was of great value to some parents was case management. It involved help with obtaining services, negotiating with agencies and systems, and assisting with the 'paperwork'. Parents often had to fight to obtain services for their children. When they had an ally who could serve as a mediator and advocate, they felt supported. ...

Parents also reported that community institutions including schools, youth groups, and churches could be helpful. For example, one parent described the way the public school gave emotional aide to her uninjured son at school while she was away caring for her child who was in a coma.

> .our junior high school had a crisis intervention class, and they made a point of taking my older son out of the class every day at study hall and allowing him to call the emergency room so that he could find out what was happening at the hospital, and they dealt with him on a daily basis.

Once again this program could have benefited from more information:

> ...he really did need the crisis intervention counseling, but the point was the counselor really didn't have the information, and neither did I, to explain to the 12-year-old what he could expect when his brother came home.

Parental commitment and coping.

Parents also drew upon personal resources and coping skills. These individuals have been through harrowing experiences that have required them to call upon the full extent of their will and faith. Different parents seemed to emphasis different ways of coping with the many challenges brought on by the injury. These included intensive commitment, persistence, angressive determination, religious faith, appreciating the progress their children made, and taking a view that some good can come of suffering. For example, here is a statement of the kind of commitment that parents have exhibited to their brain-injured children:

> I have given five years of my life for my son.

Another described his efforts to help his son rejoin the community:

> (I) try to make his life as 'normal' as it can be and, I saw him...as being a very active outdoors type boy... so now I find myself helping like in Boy Scouts. I've been a den leader in Cub Scouts for three years...baseball, I've gotten him into baseball, basketball...I've been there to help with the coaches and have given him some help...(to see that) he has individualized help all along.

Our interviews included discussions with parents whose injured children have grown up and entered adult life. Some of these parents were still embroiled in ongoing stresses. However, it is important to note that at least six parents expressed a sense of having come to a resolution of their anguish. In both cases they were reasonably satisfied with the kinds of lifestyle and options available to their children. In one case the adult son was living in a group home sponsored by an organization that his father had helped to start. The father's satisfaction with his son's living arrangements and other services played an important part in his acceptance of the situation. Another mother was interviewed at three years since her child's injury. She talked at length about how the experience had given her a new set of values. She viewed her child primarily as a major contributor to her quality of life and that, in all, she had learned important lessons from the experience.

Discussion

We have used qualitative methodology that aims to let parents tell their own story and make their own points about their concerns. It attempts to maintain some of the integrity of parent's experience in the process of unifying themes from several different persons. If there is one "meta-theme" that emerges from listening to these voices of people in extremis it is that the human tragedy of the permanent damage of a child now takes place in the context of a set of social institutions that are only minimally cognizant of the social and emotional impacts of the trauma on the family. In this "non-system" (it is actually made up of several disparate and non communicating parts), the child is viewed as a decontextualized entity--a body to be kept alive, an arm or leg to restore, a learning repertoire to enlarge. Rarely, is the child viewed as a part of an elaborate social system, a family. Rarely is the family considered to be equally the victim of the accident that leaves these children and their relatives forever changed.

From our interviews with parents of children who were injured years ago, it is evident that parents and siblings are a vital lifelong resource for support for people who suffer from acquired brain injury. Yet from the ambulance attendants to the insurance agents, the many people who are involved in the treatment, rehabilitation, and long term support of the head injured person rarely recognize the needs of family members for information, emotional concern and empathy, empowerment to make choices and be partners in treatment decisions, and concern for the social fabric which surrounds the injured child and the family. The process of humanizing this treatment and caregiving system, of making it "user friendly" will require reform from many angles. On one level new services and resources must be created. Clearly when a parent has a lien of $450,000 put on him by the state or a child in a coma must remain at home because there is no local long-term care facility, there is a need for new societal resources. But along with additional resources, there is a need for a change in the focus of the medical and educational services that do exist. At every stage of the process of treatment and long term care for persons with acquired brain injury there is a need to treat the patient as part of a complex social network and to see parents and family members as of equal importance as foci of concern.

Some important limitations of this research must be acknowledged. First, the size of our sample was relatively small and thus the generalizability of our findings may be limited. Because there are few formal safeguards against observer bias in qualitative research, it is possible that our findings reflect to some extent our own opinions. The findings of this study should be compared to data gathered from other methodologies in order to examine its validity. A recent needs assessment of 119 family members of persons with ABI appears to support several of our themes (Devany, Kreutzer, and Marwitz, 1992). For example, ninety-eight percent of the respondents said they needed clear information and emotional support, " to have my questions answered honestly," and : "to have a professional to turn to for advice or services when help is needed". A quantitative survey with items derived from our themes could further test the validity and generalizability of our findings. Furthermore, it is important to acknowledge that there was a tremendous amount of variability in parental responses to our questions. Our effort to characterize parental experience in a general fashion may gloss over many individual differences. As briefly noted about one quarter of the parents in this study appeared to have made considerable progress in adapting to their child's condition. These parents expressed very little distress and seemed remarkably positive in the face of a difficult set of challenges. Future research should examine effective coping responses and positive family outcomes in greater detail. Despite these limitations we believe that these parental accounts could be useful in the training of professionals who work with families of persons with acquired brain injury. It is hoped that this study will contribute to generating the understanding and support that parents reported to often be lacking.

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