

Family Perspectives on Traumatic Brain Injury: Caregiver Training

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### Abstract

The purpose of this qualitative study was to explore the experiences of three caregivers, each of whom received hospital based inpatient caregiver training within the past five years and were caring for a family member with traumatic brain injury (TBI). Data gathered from interviews with caregivers revealed four major themes, one with subthemes. The themes were: 1) “Changes in Family Roles after TBI,” (2) “Need for More than Physical Training” with subthemes, “Psychosocial Support for Caregivers,” and “Social Isolation;” (3) “Expectations for Behaviors and Recovery,” and (4) “Identity Blurring.” These themes suggest that the individuals in this study likely could have gained from a greater emphasis on case-specific care that included more appropriate timing of information. Participants also expressed a desire for increased case-specific guidance for both caregivers and care receivers in dealing with psychosocial challenges and longer-term support and training after discharge from formal rehabilitation services.

Occupational therapists support caregivers through collaborative efforts to find resources for continued education. They also provide psychosocial support for caregivers at home and in their communities. Additional education about resources and support groups could help caregivers manage new circumstances and challenges. In addition, the study points to a need for more hopeful, individualized training for TBI caregivers, training tailored to their unique needs and situations.

### Family Perspectives on Traumatic Brain Injury: Caregiver Training

Traumatic brain injury (TBI) not only significantly changes those who sustain the trauma, but it also affects the lives of their family members and others who care for them at home. According to a study by Kreutzer, Gervasio, and Camplair (1994), investigating caregiver distress, the dynamics of an overburdened family may contribute to increasing difficulties in caring for a relative with TBI. Such caregiving challenges can lead to delayed or diminished recovery for those with TBI and, consequently, increase challenges for family members who care for them (Kim, 2002).

Long-term neuropsychological behavioral and personality changes in the TBI survivor are complicated and difficult for families to adapt to (Kim, 2002). In addition to short- and long-term changes in brain function that result from TBI, changes in mood are common, including “depression, anxiety, personality changes, aggression, acting out, and social inappropriateness” (Centers for Disease Control and Prevention [CDC], 2010).

Support and education programs prior to hospital discharge aim to improve the transition to home and community for people with TBI, as well as those who care for and interact with them. Few studies support or even evaluate types of caregiving intervention (programs supporting caregivers), but studies confirm the impact of brain injury on families (Oddy & Herbert, 2003). Many family members and caregivers report that their difficulties increased when access was limited to follow-up support for their caregiving (Lefebvre, Cloutier, & Levert, 2008).

Occupational therapists are specifically qualified to train caregivers and ease their frustrations. The therapist’s challenge lies in time constraints and limited insurance coverage to educate and support a growing number of family caregivers. This study analyzes caregiver

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reflections on rehabilitation education. It compared the level of satisfaction each caregiver experienced, elements they found most useful, and further education that they believe could have been helpful for adjusting to their changing family and new caregiver roles.

### **Background**

According to the CDC, TBI is a serious health problem in the U.S. Each year, 1.7 million people nationwide sustain a TBI as a result of cranial impact and other injuries that cause disruption of normal brain function. U.S. statistics indicate that falls are the leading cause of TBI (35.2%), followed by motor vehicle/traffic related injury (17.3%), injuries caused by being struck by or against an object (16.5%), and assaults (10%). The remaining 21% are attributed to other/unknown causes. Young people 0-19 years old and adults over 75 are the age groups of highest TBI incidence. In every age group, males historically have a higher rate of TBI than females. Statistics, such as these, clearly demonstrate that the groups most at risk are those most likely to need longer-term (younger people) or more extensive (older people) care-giving. (CDC, 2012a).

Although most TBIs reported annually are classified as mild, repeated mild TBIs over a short period of time are often life-threatening (CDC, 2012b). A common complication of TBI is susceptibility to further TBI due to impaired judgment or other behavioral complications. In addition, general health and neurological or psychiatric consequences of brain injury often lead to rehospitalization (Ashley, 2010). TBI can also increase risk of epilepsy, Alzheimer's disease, Parkinson's disease, and other common age-related brain disorders (National Institutes of Health, 2012).

The number of individuals in the U.S. who survive TBI is growing. More than 5 million Americans living with a TBI require permanent help to perform daily or routine activities

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(National Institutes of Health, 2012). Social systems today face the challenge of supporting these individuals as they age because TBI often has long-term effects (Homifar, Harwood, Wagner, & Brenner, 2009). A systematic review of long-term neurologic health found evidence that TBI leads to increased risk for a variety of associated neurological and psychological problems (Bazarian, Cernak, Noble-Haeusslein, Potolicchio, & Temkin, 2009).

According to Krefting (1990), long-term outcome following TBI is a major concern for health care workers, families and communities because of the lasting effects of brain injury. TBI causes long-term limitations in activity. Compared to stroke and other neurological pathologies, TBI typically affects younger people. Consequently, survivors of TBI are more likely to require longer-term care and experience higher socioeconomic costs (Van Baalen et al., 2007). The economic cost of TBI in 2010, including direct and indirect medical costs, is estimated to be \$76.5 billion (CDC, 2012a). Advances in medical science extend average lifespan for people with TBI; however the collateral effects of their injuries on themselves and their families are also extended (Lefebvre et al., 2008). These statistics and results from the above studies point to the need for increased and more comprehensive training for those caring for people with TBI.

Caring for someone with TBI can be more difficult than caring for a person with disabilities that do not involve impaired cognitive function, such as spinal cord injuries (Kreutzer et al., 1994). People who experience severe behavioral sequelae from TBI often require substantially more resources (Carnevale, 1996). Resultant psychological and cognitive symptoms that challenge caregivers include depression, limited awareness of impairment, cognitive and memory deficits, agitation, and aggression (Mackay, Chapman, & Morgan, 1997).

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Occupational therapists support and educate families in transition to caring for a person with TBI in the home and community (Radomski, 2008). Psychological and cognitive problems for people with TBI often become evident in the context of everyday living and make daily tasks and interactions with their caregivers more challenging.

Many methodologically sound studies describe the effectiveness of varied approaches to support care receivers, but few describe caregiver education or support. Boschen, Gargaro, Gan, Gerber and Brandys (2007), in a comprehensive search of the literature, found only four studies that rigorously investigated effective methods of supporting TBI caregivers. None of these four studies found a significant decrease in caregiver burden resulting from caregiver interventions. But one of the studies by Sanguinetti and Cantzaro (1987) reported that caregivers with additional training were “more informed about brain injury-induced behavior” and better prepared “to help [their] family member compensate for physical dysfunctions.” Singer et al. (1994), found reduced depression in participant caregivers after stress management and support groups were implemented, but they examined combined data from caregivers and care receivers, making it difficult to determine outcomes specific to caregivers.

Although some positive changes in caregivers of people with TBI were observed in the studies reviewed by Boschen et al. (2007), researchers found that the body of literature on the topic of effective brain-injury caregiver intervention lacked methodological rigor. Of the four studies that met the methodological inclusion criteria, no conclusive results were found to guide health professionals in developing and implementing evidence-based caregiver training programs to minimize caregiver burden and enhance their effectiveness in caring for persons with TBI (Boschen et al., 2007).

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Recently published research has also failed to find evidence that any single intervention reduced caregiver burden, although some benefits were evident. None of these recent studies found a significant effect on caregiver burden or well-being, although findings from Backhaus, Ibarra, Klyce, Trexler, and Malec (2010) suggest an increase in perceived self-efficacy among a combined group of caregivers and care receivers, making it difficult to determine the intervention's effect on caregivers exclusively. Rivera, Elliott, Berry, and Grant (2008) reported reduced depression in caregivers. Kreutzer et al., with no control group (2009), reported changes in family needs but measured neither satisfaction nor burden.

Although these studies found some benefits of varied interventions, none succeeded in identifying a caregiver intervention that successfully reduced caregiver burden or improved caregiver quality of life/satisfaction. This lack of evidence is due, in part, to the wide variety of challenges that family members face when caring for someone after brain injury (Oddy & Herbert, 2003). Even though extensive literature exists detailing the importance of interventions to relieve family or caregiver stress, there are few studies evaluating specific interventions (Oddy & Herbert, 2003) or long-term implications of care for the family (Bazarian et al., 2009).

The efficacy of current TBI caregiver interventions is unsupported by research. Perhaps the better way to address the deficiency of research is to ask the caregivers what has and has not worked for them. No reports were found on caregivers' perspectives about what information or educational support they lacked at the time of or following their family member's discharge from the hospital. An exploration of essential elements of caregiver training could point to areas where occupational therapists could enhance practice coverage to include further caregiver training and counseling (Van Baalen et al., 2007).

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The purpose of this study was to identify caregiver perspectives of the most important elements of caregiver education and to determine ongoing support needs.

### **Method**

#### **Research Design**

Because of the variances in TBI sequelae, the researcher chose a case study approach in order to explore three cases in depth and analyze cross-case themes and perceptions (Patton, 2002). The current study relied on face-to-face interviews of people caring for TBI survivors (see Appendix A for sample questions). Interviews were designed to determine the participants' opinions of caregiver training during the hospital rehabilitation process, and they concentrated on identifying what educational topics caregivers found most helpful, which topics they would have liked to have had more information about, and in which areas they still felt a need for support. Case studies are limited in generalizability; nevertheless this study provides a step toward understanding the experiences of people caring for survivors of TBI.

#### **Participants**

The researcher interviewed three adult caregivers who have been living with and caring for a family member with TBI, discharged from inpatient rehabilitation at least 6 months but less than 5 years ago. People caring for children (younger than 18) or for a family member with psychosis, premorbid developmental disability, or substance abuse were not selected for the study because these characteristics may have added unique challenges that warrant attention but extend beyond the scope of this study. The researcher recruited participants through purposive sampling and snowball sampling, at community-based organizations that serve people with TBI in the Puget Sound area of Washington State and at a university-based occupational therapy clinic.

## **Procedures**

University Institutional Review Board (IRB) approval was obtained before the study was implemented. The researcher distributed recruitment fliers describing the study and providing contact information for the researcher to four support group facilitators in the Tacoma/Seattle area. Facilitators were asked to post information on meeting bulletin boards and brain injury support group blogs and websites. She also distributed fliers to one university-based occupational therapy clinic and sent an email to all clinic therapists, explaining the study and requesting referrals.

Prior to data collection, the researcher conducted a mock interview with a professor at the university in order to practice interviewing skills and evaluate possible questions prior to beginning data collection.

Participants were reminded of the purpose of interviews, and each participant was given an informed consent form for signature. After obtaining informed consent, demographic information was collected, including age, sex, date and cause of care receiver's injury, education levels of caregiver and care receiver.

The initial interview lasted 45 to 90 minutes and took place in a mutually agreed-upon meeting place. A list of prepared questions was used; however the researcher asked each subsequent question based on the previous question's response (See Appendix A for sample questions). All interviews were audio recorded and transcribed verbatim. Names were changed on all transcribed documents to ensure confidentiality, and all recordings were destroyed after the tapes were transcribed.

Follow-up interviews of approximately 30 minutes were conducted within one month, one in person and two by telephone, consisting of questions designed to promote understanding

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of any unanswered interview questions and to verify participant answers (see Appendix B for sample follow-up questions). Member checking confirmed basic accuracy of participant statements during the second interviews.

### **Data Analysis**

Data for this study consisted of the initial 45- to 90-minute interviews with the three participants, as well as a follow-up interview data. Data analysis began with open coding, which consisted of identifying and describing concepts that emerged from the data. Codes were then organized into categories; concepts were further analyzed to describe meanings and relationships and, finally, developed into themes.

### **Results**

The three caregivers who participated in this study had all been caring for and living with a family member with TBI. Two of the participants' experience was caring for an adult son who was relatively high-functioning, and one cared for a son whose TBI resulted in functional limitations severe enough to qualify him for extensive daytime care from caregivers paid for by the state. Each participant had a different personality and unique caregiving role. Participants and their sons were given pseudonyms to protect confidentiality. A brief description of the participants is provided here to provide context to the themes and supporting quotes that follow.

Laurie and Doug are married and share responsibility caring for their highly functioning son Daniel, injured in 2008. They live in a small rural community. Laurie is a teacher, and Doug has a night job so he can be with Daniel during the day. They do not have any hired caregivers. Laurie and Doug were interviewed separately.

Carrie is also married. She and her husband share caregiving responsibilities for their son Kevin. They lived in a rural community prior to their son's accident and had built a house there,

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intending to live in it for the rest of their lives. In order to provide a safer, more enriching and accommodating environment for their son, they moved to a city neighborhood with access to public transportation for people with disabilities. They receive supplemental caregiving provided by the state due to the severity of Kevin's injury. Initially, after Kevin's injury in 2005, he went to a nursing home. In 2008, Kevin's parents were able to negotiate a return to hospital rehabilitation, where the family received further caregiver training. Carrie was interviewed individually. Her husband was not a participant in the current study.

Despite the differences in individual circumstances, interview data across participants revealed four major themes. The first theme was "Changes in Family Roles after TBI," in which the participants discussed not only balancing the family's post-accident roles but also further necessary adjustments involving their sons' return to independence. The second theme was the "Need for More than Physical Training," including two subthemes: "Psychosocial Support for Caregivers" and "Social Isolation." The third theme, "Expectations for Behavior and Recovery," described how caregivers in this study viewed inaccurate predictions expressed by the health care team and how those inaccurate predictions impacted caregivers' attitudes toward their sons' recoveries. The fourth theme, "Identity Blurring," developed from observations that when caregivers were asked about their experiences they often reported information about their sons' experiences. All of the participants gave examples of how the standard information that they received on what might happen was not very close to what happened in reality.

### **Changes in Family Roles after TBI**

Participants were asked how things changed for their family and how well they thought rehabilitation staff was able to prepare them for their new jobs as caregivers. All participants expressed major changes in their lifestyles and daily roles, including caring for and "re-raising"

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an adult child and concern for the care of their children in the future if the family caregivers became unable; attention taken away from other family members (e.g., grandchild, siblings); and changes in marital relationships.

When asked if anyone talked to her in the hospital about changing roles, Laurie replied, “You know, there isn’t a lot of training for that.” She also said, “When he first came home... We were it. We were everything, his dad and I.” Doug also expressed a similar realization that adjustment was challenging. “It’s like caring for a two-year-old all over again,” he said, “except he’s bigger and he falls harder.” Similarly, Laurie commented, “I’ve wrapped my little wings around him again and, you know, re-raised him – basically we raised him twice; this is our second time around.”

When asked about her experiences with “re-raising” her son Kevin, Carrie mentioned their mutual discomfort with the confusion of caregiver and parenting roles, as evidenced by the statement, “Moms don’t see their 25- to 26-year-old son’s private parts. [They] just don’t.”

Participants discussed ways their own independence was challenged by their new caregiving roles. They also expressed interest in promoting their sons’ independence in order to reduce their caregiving burden as well as benefit the sons. Laurie described the complex problem with her son:

He didn’t like being away from home... He’s very attached to me... You couldn’t hardly get him away; they didn’t say that that might happen... He couldn’t stay alone, so he had to go everywhere we went.

Doug mentioned in response to a question about his son’s independence, “The last year or so we started leaving him by himself a little bit more, and we get to go out and you know, have a date night.” Doug also expressed his perspective related to lifestyle changes in relation to

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his own and his son's lack of independence. "It was kind of hard, actually. We had to give up what we normally did to make sure that he was able to do what he needed to do."

Laurie mentioned that she also struggles with finding the right balance as a caregiver and mother in helping her son Daniel become independent:

I would like help with him learning to – to leave and get out, and go do things without a caretaker. And he would like that, too, because I – I think at times I suffocate more than help.

When Carrie was asked about how her son Kevin's lack of independence affected her independence, she answered:

[Kevin] really doesn't have any independence... I grieve a lot about that. If I'm going to go into tears it's just thinking about his total dependence on other people. My husband and I love him, and we care for him, and so as long as we're able to, he will have someone who loves and cares for him. But what's he going to do when we're gone? Or we can't? And so it's really sad to me that he doesn't have the independence... Sometimes he wets the bed... If nobody took care of him he would die there.

The above concern was an echo of something that Carrie had said earlier:

They never talked to me about what's going to happen to him in the future, you know, if we – if we died or became unable to care for him. I guess that's something we're going to have to seek out on our own.

Carrie and Laurie both expressed difficulty managing caregiver roles along with other family roles, including being a parent and grandparent. Carrie stated:

I think that for my husband and I, the hardest thing was with our [youngest son]. We adopted him when he was five in 2002, and [Kevin's] accident was in 2005. Our family was still adjusting ...even though he's a pretty cool kid. We were figuring that we would be able to really focus on him because he has special needs. And then suddenly, [when Kevin had] the accident, focus got off [our youngest son] for a while and onto [Kevin]. That was hard for [us all]. [My husband] would really focus on [Kevin], and sometimes we had to talk about it. [I'd say] "Hey, when I walk in the door I need you to not say, '[Kevin] did this. [Kevin] did that.'" You know, [instead I needed him] to say, "Hi, how was your day?"

Laurie also described challenges to pre-caregiving roles:

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One of my grandchildren was born during the time that [Daniel] was still in ICU. I don't think that I got to spend as much time with the new grandchild because my attention was on [Daniel]. [Daniel] has been our primary concern for the last few years: first comes him and then comes everybody else. And I'm not sure how the other kids really feel about that, but we just did.

When talking about how her married life changed after her son's accident, Laurie emphasized, "My husband and I are together on the caretaking. The teamwork is a big, big part of it." Doug also emphasized the importance of teamwork, although he related it to his son's recovery and not his own well-being. "The main thing is that the [patients] who do better have a lot of family support."

Carrie also commented about how the impact of caregiving impacted her marriage:

I think that our relationship is stronger now than it ever was. We do have differences in how we think [Kevin] should be dealt with. Like sometimes I don't think [my husband] should do or say something that he says or does. Or he thinks I shouldn't do or say something that I do, and that'll cause some tension. But I think that by-and-large our relationship has grown together more. I will have to tell you that we have a very strong faith. I really truly believe that that has been the thing that has made a difference – that we have not only grown closer to each other but as Christians we've grown closer to the Lord. And he has given us strength that probably we couldn't have [otherwise] had.

### **Need for More than Physical Training**

Repeatedly, participants expressed satisfaction with the training that they received to care for their sons' physical needs, but they also all mentioned a desire for training that addressed needs. The unmet needs that they described usually had to do with ways of dealing with their own limited access to and increased need for psychosocial support. Interestingly, they seemed to imply that their sons' lack of psychosocial support and social isolation was also something that they would like help in managing.

**Psychosocial support for caregivers.** All participants emphasized the desire for help with their own and their sons' psychosocial adjustment to daily living. Laurie said:

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They gave us really good care on [taking care] of him physically, but I think the mental part could have been better...as far as mentally how hard it was going to be... they were very insistent on, “Get a life. Have fun. Go out. Go do what you need to do now because it’s gonna change when he comes home.” Well, [we] didn’t really understand what they meant, but I do now, how much life changes. I mean, we were down to no kids at home. No kids that we had to tend to, or to answer to, or to look out for, or anything else. They were all doing their own thing, and we were about to enter the golden years. It’s like parenthood. You don’t know what you’re getting into for real. You could read all the baby books you want, but until you’ve walked it you really don’t know.

When asked what they would have liked to have more training about, participants answered that they would have liked more focus on areas that went beyond physical instruction. Doug brought up a point, also mentioned by the other participants, that he would have liked more psychosocial help, but he seemed to have a difficult time specifying exactly what form of help would be most effective, stating, “Maybe some more – I don’t know – psychological [help] or...but every case is so different that I don’t know if they could have prepared us any better.”

Carrie expressed that support groups were, “really important to us. I think that’s been one of the main things...learning from other peoples’ experiences, and gaining information, and knowledge, and support that way.”

In contrast, Laurie reported about her one experience attending a support group with one of her friends: “Trying to get Daniel to go that support group didn’t work because again, I don’t mean anything bad here but [my friend’s son] is severely, severely brain injured.”

Carrie reported that support groups have been essential to her. Laurie expressed a lack of interest after one frustrating experience. Doug mentioned that:

We haven’t really [gone to support groups] – we’re probably just as bad as [Daniel]. We know we need to do that, to look into some. [Laurie] has some friends that she talks to about that burnout stuff, and bounces ideas off other people.

**Social isolation.** The subject of social isolation was mentioned with all participants in reference to themselves as well as to their sons, and as a need for inclusion as a discussion topic in caregiver training.

Social life is hard. That's probably, as a caretaker... one of the hardest things now. We've gotten past the physical part... Now it's the social part... It's just – it's a heartbreaker. He's always had a lot of people around him. He's always been a people person. After the accident it was family; that was it. (Laurie)

And Doug said:

A lot of stuff they went over... We thought would never happen, you know. Though I recall one meeting where [a parent was] telling us about all her son's friends, how he had a lot of friends, and then... I think he had a stroke or something... You know, they would start after he got home from the hospital they would come over, and then as time went by...they just kept dropping off, and now he has nobody coming over. And, you know, I can remember [my wife saying] "Oh, no, that'll never happen. He's got so many friends." But it pretty much did.

All three participants mentioned changes in their own social lives in relation to their caregiving roles. When the researcher asked Carrie about how caregiving responsibilities affected her social life, Carrie responded:

[For example], Thursday, the [paid] caregiver was going to be there till 9:00. I have this group of ladies... We have been having a class together for a whole year. It was our last class - our last thing we were going to do - go out to dinner together. And just before I left work...I talked to [my husband], and he said, "[The paid caregiver] called, and he's not going to be there."

Laurie responded to the same question, "What about your social life?" by commenting:

"I go to work. I get out... and I love my job.

Carrie expressed disappointment in limitations in family trips because of Kevin's needs, for example, she said: My husband's going to take our youngest son hunting. Well it would be really fun for me to go with them. They're going to go to this ranch and it'd be really cool. They have horses and all this stuff and it'd be really great, but how could we do that? And, you know, we have friends in Costa Rica who want to have us come visit. How are [we] going to do that?

### **Expectations for Behavior and Recovery**

One of the most prevalent themes across all three participants was the concept of the health care team's expectations of how their son would recover that did not manifest, such as expecting that their son would recover less than he actually did. They all three discussed these expectations when asked to describe briefly their son's accident.

Carrie's son later made small progressions after she and her husband were offered the choice about whether or not to take him off of life support.

They give you this information about how people come out of a coma, and [Kevin] didn't do what they said... [They said that] he would start to wake up, he would start to move around, you know. He'd start to talk. It would be random...maybe start to walk around, and you'd really have to watch him...But he never walked. And he never talked. And he never had the thrashing around like we saw some of the other young guys do. It was really different. It was really sad, because you know, you're expecting you know, things to progress, and you know, they didn't. (Carrie)

Laurie's son also had a surprising recovery:

Right after surgery, the surgeon came in and explained about...the damaged areas –what those areas did [and that] they were pretty extensively damaged...but he's...remarkable...it's an amazing, amazing thing. When we see the nurses at [the hospital] that took care of him when he first got there, they just can't even believe it.

Carrie also expressed happily that her own son's recovery was better than expected, and that she would have appreciated, "a little bit of hopefulness," She said:

Most of the people were not very supportive. You know, they were, you know, you – it's going to be – "He's going to be like this forever, and if you think otherwise, you are mistaken." And, you know...pat you on the head [and say] "Oh, too bad, but, you really need to face reality." And we just decided that we would never give up hope, and we would continue to infuse [Kevin] with a sense of hope. They can say what they want to say, but we haven't ever given up. And I think, [what might help is] just being more hopeful with us, not saying we're, you know, we're foolish for thinking that our son could do better.

### **Identity Blurring**

All three participants had a tendency during the interviews to respond to questions about their caregiving experiences or personal well-being, with statements or stories about their sons' experiences. For instance, when the researcher asked Doug to describe the training and education that he received to care for his son, he answered by discussing what happened to his son rather than his experience:

[When] they took him out of ICU he started waking up slowly. We went over to [the hospital] after that for rehabilitation. The first few weeks were just him...all the therapies.

In response to questioning about what the hospital staff suggested about her own well-being, Laurie began her response regarding lack of a network to support her well-being, but immediately shifted into a description of her son's needs, shifting away from her own:

There wasn't a – a network for that, really. It's getting better, you know. He likes it when I leave him alone – I leave him alone to run to the grocery store, or whatever, you know, and he likes that independence. But he's a fall risk, and so him being a fall risk makes it scary, because there's times that I'll say, "Where'd you get that mark on you?" a bruise on his arm, whatever. "I don't know." So he falls and doesn't remember that he fell.

### **Discussion**

This study revealed four themes that were derived from the experiences of caregivers for people with TBI. Throughout all three interviews and all four themes, regardless of their specific circumstances, participants expressed a lack of assistance with adapting to new psychosocial considerations and a wish for more support in this area, although they also expressed uncertainty about how they could have been prepared for the unknown.

One participant reported that support groups have been essential to her. Another expressed a lack of interest after one uncomfortable experience. It seems possible that there is some confusion around the functions and purposes of support groups that the occupational

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therapist could clarify. Participants reported different perceptions on support group experiences. Participants expressed frustration with having been “taught” what their son’s likelihood of improvement in daily living skills would be. In both participants’ experiences, these estimations proved to be incorrect, and their sons were actually able to participate in daily living activities much more than expected. This points to a need for what one participant called “hopefulness.”

In other words, what participants suggest is needed is a shift in emphasis from a listing of possible problems approach to a more hopeful advocacy approach that, considers the unique circumstances of each family and educates family members about the importance of continued psychosocial support, its benefits and how to access it. Also suggested by Laurie’s interview was the misperception that support groups are only places for the care receiver to be with peers who have sustained similar injuries and have similar recoveries. Occupational therapists can help caregivers by clarifying and discussing the purposes and benefits of support groups. They can also help by providing concise lists of resources and theirs or another hospital employee’s contact phone number for referrals in the future as they become necessary.

### **Implications for Occupational Therapy**

Data from this study suggest that there is a fundamental flaw in our health care system with regard to the availability of timely psychosocial help and training for caregivers for people with TBI. Since the health care team is not certain what the nature of recovery and ongoing impairments will be for each patient, they are unable to prepare families completely. In a perfect world, long-term support and education would be provided by both health care workers and the community. The interviews in this study suggest that it would be helpful if occupational therapists and other health care providers would educate caregivers about general areas of difficulty and where to go for help instead of emphasizing the details of each disastrous

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possibility. It is important for occupational therapists to emphasize to caregivers that support groups, in addition to being a potentially therapeutic social interaction and for people with TBI, are often educational, so can meet new needs for caregivers as they arise. It also seems crucial that occupational therapists educate individuals caring for a family member with TBI about how support groups can be an opportunity to gain support through giving support.

### **Limitations**

Considering the scope of the current study and time limitations, saturation of data was not achieved. Additionally, participants were selected partially due to the convenience of the researcher, and their experiences do not represent those of all caregivers for people with TBI. The two care receivers in this study did not have many of the challenging behavioral problems noted in the literature, so caregivers managing behavioral problems may identify a different set of priorities for caregiver education. Also, time since discharge of care receiver in both cases was more than three years. Consequently, the caregivers' memory of education may not be "robust."

### **Future Research**

Participants caring for individuals with TBI have provided perspectives that supplement the existing literature describing occupational therapy approaches from the viewpoint of therapists. Interviewing caregivers who provide full-time care about the adequacy of their rehabilitation caregiver training may reveal a more accurate picture of what additional changes to training need to be made. It would also be interesting to investigate perspectives of caregivers in family roles other than those in this study, such as children, spouses, or other friends and relatives. Additional studies interviewing caregivers for individuals with more prominent behavioral sequelae would help to discover additional caregiver concerns and reveal a broader picture of TBI caregiver training experiences. Lastly, interviewing occupational therapists who

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educate TBI caregivers and getting their responses to the perspectives and ideas revealed by the current study would likely yield new insights into how caregiver training can be enhanced.

### **Conclusions**

In considering the perspectives of caregivers in this study, there is a need for more timely education regarding psychosocial issues of caregiving support at discharge from TBI rehabilitation programs. The present health care system does not reimburse for long-term or follow-up training for most TBI caregivers. Occupational therapists can address this problem, adapting to the realities of the emerging health care climate, by advocating for caregiver social support and emphasizing its value during caregiver training. Related to this need for more supportive education is the need for all health care providers' restraint in listing possible outcomes for patient recovery. Instead, a more hopeful attitude will help caregivers adapt more comfortably to the major life changes that follow TBI.

## Appendix A

**Sample Interview Questions**

**Grand Tour Question:** Tell me about the training and education you've had to help you care for your family member/friend with a traumatic brain injury.

- Did the training that you received include suggestions or encouragement for maintaining your own psychological health? Were you educated about safe body mechanics? Do you feel that the training you received educated you sufficiently about the common behaviors resulting from TBI?
- Did you receive education focused on your family member/friend's case-specific challenges?
- Did the training that you received include any advice (problem-solving strategies/coping skills education) about how to deal with challenging post-TBI behaviors?
- Did the training that you received include your family member the care-receiver in any of the discussions regarding caregiving skills?

In reference to your caregiving role, what are your biggest concerns and remaining needs at present?

- Were you given referrals (from hospital staff) to brain injury support groups?
- What kinds of changes have there been in your needs for education?
- What would you still like help with?

What were the most valuable aspects of training for you?

- Which techniques that you were taught, do you still use every day (physical, behavioral, self-care)?

## CAREGIVER TRAINING AFTER TBI

- Can you think of any one thing that you were taught that was indispensable in each of these three areas (physical, behavioral, self-care)?

Was there anything that you wish would have been included in your training?

- If you could go back and repeat sections of the training with the experience that you have today, which sections would you repeat? Why?
- Are there any areas that you wish would have been emphasized more?

## Appendix B

### Follow-up Interview Questions

- Are there any topics from our last interview that you would still like to discuss?
- Can you tell me a little bit more about\_\_\_\_\_?
- When you said \_\_\_\_\_ did you mean\_\_\_\_\_?

## References

- Ashley, M., Ed. (2010). *Traumatic Brain Injury* (3<sup>rd</sup> ed.). Boca Raton, FL: Taylor and Francis Group.
- Backhaus, S. L., Ibarra, S. L., Klyce, D., Trexler, L. E., & Malec, J. F. (2010). Brain Injury Coping Skills Group: A preventative intervention for patients with brain injury and their caregivers. *Archives of Physical Medicine and Rehabilitation*, *91*, 840–848.  
doi:10.1016/j.apmr.2010.03.015
- Bazarian, J., Cernak, I., Noble-Haeusslein, L., Potolicchio, S., & Temkin, N. (2009). Long-term neurologic outcomes after brain injury. *Journal of Head Trauma Rehabilitation*, *24*, 439–451. doi:10.1097/HTR.0b013e3181c15600
- Boschen, K., Gargaro, Gan, C., Gerber, G., & Brandys, C. (2007). Family interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. *NeuroRehabilitation* *22*, 19–41.
- Carnevale, G. (1996). Natural-setting behavior management for individuals with traumatic brain injury: Results of a three-year caregiver training program. *Journal of Head Trauma Rehabilitation*, *11*, 27–38.
- Centers for Disease Control and Prevention. (2010). *What are the potential long-term outcomes of TBI?* Retrieved from <http://www.cdc.gov/TraumaticBrainInjury/outcomes.html>
- Centers for Disease Control and Prevention. (2012a). How many people have TBI? Retrieved from <http://www.cdc.gov/traumaticbraininjury/>

- Centers for Disease Control and Prevention. (2012b). *Severe Traumatic Brain Injury*. Retrieved from <http://www.cdc.gov/TraumaticBrainInjury/severe.html>
- Homifar, B. Y., Harwood, J. E., Wagner, T. H., & Brenner, L. A. (2009). Description of outpatient utilization and costs in group of veterans with traumatic brain injury. *Journal of Rehabilitation Research & Development*, *46*, 1003–1010.  
doi:10.1682/JRRD.2008.12.0166
- Kim, E. (2002). Agitation, aggression, and disinhibition syndromes after traumatic brain injury. *Neurorehabilitation*, *17*, 4, 297-310.
- Krefting, L. (1990). A descriptive study of family directed therapy for traumatically injured persons. *Occupational Therapy in Health Care*, *7*, 87–99.
- Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury*, *8*, 211–230.
- Kreutzer, J. S., Stejskal, T. M., Ketchum, J. M., Marwitz, J. H., Taylor, L. A., & Menzel, J. C. (2009). A preliminary investigation of the brain injury family intervention: Impact on family members. *Brain Injury*, *23*, 535–547. doi:10.1080/02699050902926291
- Lefebvre, H., Cloutier, G., & Levert, M. J. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, *22*, 535–543.  
doi:10.1080/02699050802158243
- Mackay, L. E., Chapman, P. E., & Morgan, A. S. (1997). *Maximizing brain injury recovery: Integrating critical care and early rehabilitation*. Gaithersburg, MD: Aspen.
- National Institutes of Health. National Institute of Neurological Disorders and Stroke. (2012). *Traumatic brain injury: hope through research*. Retrieved from [http://www.ninds.nih.gov/disorders/tbi/detail\\_tbi.htm#169963218](http://www.ninds.nih.gov/disorders/tbi/detail_tbi.htm#169963218)

- Oddy, M., & Herbert, C. (2003). Intervention with families following brain injury: Evidence-based practice. *Neuropsychological Rehabilitation, 13*, 259–273.  
doi:10.1080/09602010244000345
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage.
- Radomski, M. (2008). Traumatic brain injury. In M. Radomski, & C. A. Trombly Latham (Eds.), *Occupational therapy for physical dysfunction*, (6<sup>th</sup> ed., pp. 1042-1078). Baltimore, MD: Lippincott Williams and Williams.
- Rivera, P. A., Elliott, T. R., Berry, J. W., & Grant J. S. (2008). Problem-solving training for family caregivers of persons with traumatic brain injuries: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation, 89*, 931–941.  
doi:10.1016/j.apmr.2007.12.032
- Sanguinetti M., & Catanzaro, M. (1987), A Comparison of discharge teaching on the consequences of brain injury. *Journal of Neuroscience Nursing, 19*, 271-275.  
doi:10.1097/01376517-198710000-00010
- Singer, G., Glang, A., Nixon, C., Cooley, E., Kerns, K. A., Williams, D., & Powers, L. E. (1994). A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. *Journal of Head Trauma Rehabilitation, 9*, 38-49.
- Van Baalen, B., Ribbers, G. M., Medema-Meulepas, D., Pas, M. S., Odding, E., & Stam, H. J. (2007). Being restricted in participation after a traumatic brain injury is negatively associated by passive coping style of the caregiver. *Brain Injury, 21*, 9.