Understanding the Lived Experience of Caregivers for Children with a Traumatic Brain Injury

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Introduction

Background:

- Kirk et al. (2017) observed that parental stress, financial burdens, and strain on family relationships often accompany pediatric TBI, impacting long-term outcomes (p.304).
- There are varying degrees of disability that depend on the severity of the brain injury, and different deficits related to the severity will be seen in the years to come. These potential deficits include but aren't limited to, physical, cognitive, emotional, and behavioral deficits (Popernack et al., 2015). Deficits related to the severity of the brain injury also determine the financial and emotional impact on the child's family, specifically the caregivers.
- The severity of the child's TBI will also affect the caregiver's role in providing their child with the necessary support as current literature has shown that there is a significant correlation between a severe TBI and caregiver distress or burden (Rollins, 2013).
- This will directly impact the suggestions made by the child's discharge planning team when determining the child's therapeutic needs after discharge. The discharge team will need to be aware of the barriers that might prevent children and their caregivers from having adequate follow-up adherence. These barriers could include the distance between their home and the service they are seeking, lack of transportation, negative feelings towards the clinical environment, and challenges when remembering schedules (Spaw et al., 2018).
- Identifying the strategies occupational therapy could use to improve discharge planning and promote the continuum of care could positively impact the caregiver's feelings of burden and burnout.

Relevance to Occupational Therapy:

Research surrounding the impact on a caregiver of a child with a traumatic brain injury is lacking, but there is research addressing the impact on a caregiver of an adult with a TBI and similar conditions. The dramatic changes in the caregiver's life including their roles, routines, rituals, and mental health clearly align with occupational therapy practitioner (OTP) services. A barrier to OTPs providing direct services to the caregiver while providing services to the child is that it falls out of the OTP scope of practice (Demers, 2022). For the OTP to provide the best care to the child, they must also address the caregiver's needs as it will directly impact the child's recovery and progress post-hospitalization.

Theory:

The delivery of family-centered care is comprised of collaborating with the family when making health-care decisions, educating throughout their child's hospital stay, and respecting the family and their needs. King et al. (2002) noted that the Life Needs Model of Pediatric Service Delivery "focuses on the concept of need, emphasizes the values of family-centered services, and recognizes the strengths and capacities of the child and family" (p. 1). The Life Needs Model guides therapists throughout the distribution of their services to target the child and family's long-term goals, which could include community participation and quality of life. (King et al., 2002).

Methods

Research Design:

A qualitative phenomenological approach was used to collect data based on the participant's lived experience. Each participant participated in a semi-structured interview with the primary investigator either in person or using the HIPAA-compliant Zoom platform. The interview guide was created based on a needs assessment conducted with the Alabama Head Injury Foundation (AHIF) and a review of the current literature.

Population & Site Description:

This study was completed with AHIF, a non-profit organization that provides a multitude of services to individuals with a TBI and their caregivers.

Eligibility Criteria:

1. Caregivers who have received or who are currently receiving services at AHIF
2. Caregivers whose children were under the age of 18 at the time of their injury
3. The child is at least one-year post hospitalization
4. English is reported as their primary language

Recruitment:

Six participants were recruited to participate in this study by either word of mouth from AHIF staff or contacted by the primary investigator via email.

- 5 females, 1 male
- 3 caregivers reside in Shelby County, 1 in Choctaw County, 1 in Lawrence County, and 1 in Coffee County

Data Collection & Analysis:

Once each interview was completed, the interview was transcribed using the Zoom feature and analyzed to identify common themes based on the participants' responses. Each interview was read three times. The first time was to ensure that responses were accurately reflected, the second to fully understand the participants' experience, and the third to identify recurring themes. Inductive coding was used to derive codes directly from the data throughout the data analysis process.

Results

Theme 1: Adaptation to a New Reality

100% of the participants described the lasting impact of their child's TBI on their lives. They shared their experience with transitioning home after their child's hospital discharge and many mentioned coming to terms with their "new reality".

"You're just so overwhelmed at the beginning, just trying to realize. Put all the pieces of your life back together. Not only help your child survive but see what this new life is going to be."

Heightened Emotional Response

The participants interviewed described experiencing intense emotions when their child first sustained their TBI. The participants shared that they felt "terrified", "overwhelmed", "angry", and "exhaustion".

"I felt scared. I felt very scared. I did not feel like they weren't trying to prepare me. I just didn't feel that I could take care of him like they were taking care of him."

Theme 2: Barriers to Access

60% of the participants stated that they encountered physical, financial, or informational barriers."

Physical Barrier

"For the first few months we were still doing outpatient with Children's, and we were driving there 2 times a week. We live 3 hours away from there so, that got to be very overwhelming"

Informational Barrier

"We have stacks of information, children's rehabilitative services, AHIF, and all this different stuff you can use and call for resources. You can call these people, but what do we call them for? What am I gonna use them for?"

Financial Barrier

"Our income is reduced because we don't have 2 producers anymore."

"When child 4 had her accident, I ended up quitting to stay home with her"

Theme 3: Ineffective Communication

80% of participants expressed difficulties in communicating with various healthcare professionals and reported negative interactions that affected their experience with hospital staff.

"I had one doctor that. you know, felt he needed to inform me that I needed to face the facts that she may never be, you know the same, and even if she makes it, she may be a vegetable and all that like."

"They had a lot of the interns rotating. One of them really irritated me, but it's just some people have better bedside manners, and he's just very to the point. And of course, being a mom, being upset, not understanding sometimes, it would rub me the wrong way."

"You know this particular person was a little bit rude, and we didn't appreciate it, so it would get taken care of and never happen again."

Discussion

Essential Takeaways:

Gaps in Support Services

This research study revealed that participants often experienced unmet needs with support services at various points after their child's injury. While many shared that they were initially provided with resources, family education, and training, they frequently expressed uncertainty about the next steps after discharge. Participants highlighted a lack of clear guidance on long-term care planning, navigating the healthcare system, and accessing community-based supports. Additionally, some caregivers felt overwhelmed by the sudden shift in responsibilities and unprepared to manage their child's complex needs at home. Many suggested that ongoing follow-up services, peer support groups, and more individualized post-discharge planning could significantly improve their ability to provide care and maintain their well-being.

Emotional Impact

Participants described the profound emotional and psychological impact of their child's TBI on their mental health, daily routines, role identity, and ability to engage in self-care and leisure activities. Many expressed experiencing intense emotions, including anger, guilt, and fear, especially during the challenging transition home and the uncertainty that accompanied such a significant life disruption. Despite these hardships, participants also highlighted the invaluable support they received from their communities, which provided comfort during this difficult time.

Continuity of Care

Participants reported feeling most prepared when they met weekly with their child's healthcare team and felt comfortable addressing concerns and asking questions. They also emphasized the value of hands-on training and education provided throughout their hospital stay. However, during the transition from hospital to outpatient services, some participants noted a decline in the quality of care. This was attributed to factors such as living in rural communities with limited access to services and reduced communication between healthcare providers.

Discussion (continued)

Implications for Occupational Therapy Practice:

Occupational therapists play a vital role in supporting caregivers of children with TBI by providing tailored education and training that addresses the child's specific needs. OTPs act as bridges between families and the healthcare team, ensuring clear communication and continuity of care throughout the recovery process. By creating family-friendly care plans and linking caregivers to outpatient or community resources, OTs can help reduce the uncertainty and isolation that often follows hospital discharge. Beyond direct care, OTPs can advocate for systemic improvements by collaborating with healthcare providers to address broader barriers affecting caregivers. This ensures that caregivers' voices are heard, and their needs are prioritized in the development of policies and programs.

Recommendations for Future Research:

Essential recommendations to further understand the unmet needs impacting caregivers of children with TBI include conducting studies with larger and more diverse sample sizes to enhance the generalizability of the findings. Future researchers should also investigate the impact of system-level barriers, such as gaps in healthcare policies, accessibility of services, and socioeconomic disparities, to identify the systemic factors contributing to caregivers' unmet needs. Additionally, exploring the effectiveness of existing support programs and community-based resources to assess the current interventions utilized to support caregivers. Longitudinal studies are also recommended to examine how caregivers' needs evolve over time and across different stages of their child's recovery, from acute care to outpatient services.

Limitations:

Identified limitations include limited generalizability, small sample size, potential for sampling bias, and limited representation of varying demographics.

Conclusion

This research has identified the recurring unmet needs that caregivers face throughout their child's TBI recovery, including adapting to changes caused by the injury, managing the emotional impact, and navigating barriers during life transitions. OTP's role in addressing these gaps in care can improve the caregiver's confidence and ultimately improve their child's outcomes across their lifespan. OTPs can address these gaps by providing family-centered education throughout the child's recovery, enhancing multidisciplinary communication, and connecting caregivers to essential resources.

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