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Engaging Key Stakeholders to Improve Rehabilitation Care for Ohio Children with Traumatic Brain Injury

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Embargo Request: We are requesting a 2-year embargo from making the full-text report publicly available. Dissemination of this report into the public domain during this time frame may impair our goal to publish these findings in a peer-reviewed journal. We permit a record of our report to be visible, but we are requesting it only include metadata, such as the title, author, year, and executive summary.

Introduction

The chronic nature of a pediatric traumatic brain injury (TBI) and the potential negative impacts to long-term education, employment, health, and quality of life (Corrigan & Bogner, 2008; Corrigan & Hammond, 2013) pose a significant burden to public health and healthcare costs in the United States (Centers for Disease Control and Prevention, 2018). Although comprehensive follow-up after TBI is critical, research suggests that most children with TBI do not receive adequate care over time, with low rates of service utilization and high rates of unmet needs (Gerrard-Morris et al., 2009; Howarth et al., 2016; Slomine et al., 2006; Spaw et al., 2018a). While emerging evidence identifies how gaps in care provision occur, little research focuses on stakeholder-driven methods to mitigate these challenges. To address this research-to-practice gap and improve rehabilitation care for children with TBI, this project incorporates the perspectives of both caregivers and medical providers to develop recommendations for specific strategies that could target the needs of these key stakeholders. The objective of this project was to engage key stakeholders in semi-structured interviews and focus groups to determine ways to improve the current standard of care to better meet the needs of parents of children with TBI.

Specifically we aimed to (1) identify the long-term needs of children with TBI and the tools and strategies that can be used to improve service provision for children with TBI from the caregivers' perspective and (2) identify the tools and strategies that can be used to improve service provision for children with TBI from the perspective of medical providers, based on themes identified during caregiver interviews. Semi-structured interviews and focus group transcripts were analyzed using qualitative data analysis methodology to identify themes across

participants. The project included 20 caregivers and 5 focus groups (total of 29 medical and educational professionals). Themes identified from interviews with caregivers indicate that mental health support, limited transition support from hospital-to-home, and later developing academic challenges are persistent barriers faced by families as they decide whether to seek long-term care for their children following TBI. Focus group participants identified possible targets to improve care including establishing support groups for caregivers and survivors, enhancing methods of education regarding injury and transition to home, and funding a care coordinator to follow families long-term. Findings from this study have important and immediate implications for medical providers, researchers, and policy makers. Information from this study will help us develop and research clinical tools with the potential to improve long-term outcomes for the thousands of children and families affected by TBI.

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Executive Summary

In 2013, an estimated 200,000 children and adolescents in the Midwest visited an emergency department or were hospitalized after sustaining a pediatric traumatic brain injury (TBI; Chen et al., 2017). In 2014, approximately 4,000 children were treated in Ohio emergency departments with sports-related TBIs (The Ohio Brain Injury Program & The Brain Injury Advisory Committee, 2018). These trends indicate that children with TBI represent a significant proportion of trauma related care in Ohio. Following TBI, children can experience both persisting impairments and those that emerge over time; therefore, comprehensive follow-up is critical for long-term success (Centers for Disease Control and Prevention, 2018; Haarbauer-Krupa et al., 2017). However, our previous work with this population suggests that children who sustain a TBI may not consistently receive timely follow-up care (Spaw et al., 2018b), which can negatively affect their recovery. Past research has identified factors that may lead to unmet or unrecognized needs following TBI: poor family functioning, lack of insurance coverage, and limited understanding of the chronic nature of TBI (Fuentes et al., 2018; Howarth et al., 2016; Kingery et al., 2017; Slomine et al., 2006). Yet, previous studies have failed to include the voices of caregivers of children with TBI to determine how best to identify and overcome the challenges that preclude families from receiving necessary services after TBI. In addition, institutions often implement initiatives without considering caregiver and family perspectives in an attempt to improve care provision. Without the systematic inclusion of these key stakeholders' perspectives, we are missing crucial insights that could lead to meaningful change in the long-term care and rehabilitation of children with TBI.

Given these gaps in knowledge, our long-term goal is to reduce unmet and unrecognized needs for Ohio children with TBI by improving the system of care through direct inclusion of those most impacted by TBI – children, caregivers, and medical providers. As a first step, the objective of this project is to engage key stakeholders via semi-structured interviews and focus groups to identify specific strategies that would improve the current continuum of care to better meet the long-term needs of Ohio children with TBI. The rationale for this work is that, by directly engaging key stakeholders, we can develop tools or strategies that will target the needs they identify, and thus, increase the likelihood of improving outcomes. The following specific aims were addressed in this project:

AIM 1: Identify the long-term needs of children with TBI and the tools and strategies that can be used to improve service provision for children with TBI from the caregivers' perspective. *Approach:* During semi-structured interviews, caregivers will share their perspectives about their needs related to TBI care and generate ideas and recommendations for ways to improve care provision for survivors of TBI.

AIM 2: Identify the tools and strategies that can be used to improve service provision for children with TBI from the perspective of medical providers, based on themes identified during caregiver interviews. *Approach:* During focus groups, medical providers with knowledge of the current system of care will share their perspectives on long-term needs related to TBI service provision and incorporate suggestions provided by caregivers to identify strategies that would improve care delivery for survivors of TBI.

The results of this work will have a *significant positive impact* in both the short and long-term. In the short term, the identified needs and recommended strategies provided by caregivers will be immediately shared with medical providers who will help to determine the logical next steps for the creation of a set of recommendations and/or strategies to improve follow-up care for survivors of TBI. Stakeholder input will create an avenue for moving toward our long-term goal, which will involve using results from this project to generate clinical recommendations and/or prototype tool(s) that could be trialed with a group of key stakeholders. Because these interventions will be based on stakeholder input, the proposed project will ultimately provide researchers and clinicians with ideas for tools and strategies that could then be merged with evidence-based interventions to allow for better long-term management of TBI.

Qualifications

We assembled an experienced team of researchers to assure the success of the proposed project.

Jennifer P. Lundine, PhD, CCC-SLP was the Principal Investigator of the proposed study. Dr.

Lundine is an Assistant Professor in the Department of Speech and Hearing Science at The Ohio State University (OSU) and the director of the Childhood Cognition, Communication, and Brain Injury Lab (CABI Lab). She is also a clinical researcher at Nationwide Children's Hospital (NCH), where she supports research within the Division of Clinical Therapies and the Inpatient Rehabilitation Program. Dr. Lundine is an affiliated faculty member of the Center for Injury Research and Prevention within the Abigail Wexner Research Institute at NCH as well. Dr.

Lundine was a speech-language pathologist covering pediatric rehabilitation at NCH for more than a decade before she returned to school for her doctorate. Thus, she has many years of clinical experience that inform her rehabilitation research agenda. In support of her clinical competence with this population, Dr. Lundine is board certified by the Academy of Neurologic Communication Disorders and Sciences. Dr. Lundine's clinical, teaching, and research interests include impairments associated with complex pediatric medical diagnoses, especially cognitive-communication disorders associated with TBI. Specifically, her research focuses on improving gaps in access to and utilization of services designed to support children with TBI and identifying specific approaches that would improve assessment and treatment practices following pediatric TBI. Dr. Lundine has received intramural and foundation funding to support her research. She has more than 20 published peer review papers since 2014 and is a frequent presenter at state, national, and international conferences. Dr. Lundine has a history of work with Dr. Ciccio from Case Western Reserve University, including funded grants, several published papers, as well as numerous shared research presentations at national and international conferences. Dr. Lundine has worked closely both clinically and in research endeavors with Dr. Koterba as well. Drs. Lundine and Koterba have two ongoing research projects (including one intramural and one foundation grant), and they have presented preliminary data together at multiple conferences.

Christine Koterba, PhD, ABPP was a co-investigator for our proposed study. Dr. Koterba is a board certified clinical neuropsychologist in the Department of Psychology and Neuropsychology at Nationwide Children's Hospital and an Assistant Clinical Professor of Pediatrics at The Ohio State University. She is also the attending neuropsychologist on the

Inpatient Rehabilitation Unit, where she works closely with the Rehabilitation team, families, and patients with acute brain injuries. She also serves on the board of the Brain Injury Association of Ohio where she works closely with providers, families, and survivors of traumatic brain injury. Dr. Koterba has received intramural and foundation funding to support her research examining outcomes following traumatic brain injury in children discharged from the inpatient rehabilitation unit. She has 13 published peer review papers and is a frequent presenter at state, national, and international conferences. Dr. Koterba has worked closely both clinically and in research endeavors with Dr. Lundine. Drs. Koterba and Lundine have two ongoing research projects (including one intramural and one foundation grant), and they have presented preliminary data together at multiple conferences.

Angela H. Ciccio, PhD, CCC-SLP was an additional co-investigator for the proposed project. Dr. Ciccio is an Associate Professor in the Department of Psychological Sciences at Case Western Reserve University (CWRU). In her lab at CWRU, she focuses on factors that impact children's ability to recovery/develop in the presence of a diagnosis of an acquired (i.e., new onset) and/or developmental neurogenic communication disorder with a special focus on pediatric traumatic brain injury. Dr. Ciccio also studies the use of novel service delivery models (including telehealth) to enhance access to rehabilitation/support services for these children. She has published widely on the topics studied in her lab and she is a frequent invited speaker at the state and national levels. In addition to her research focused on pediatric neurogenic communication disorders, Dr. Ciccio was the Co-Chair for the Pediatric Rehabilitation Networking Group of the American Congress of Rehabilitation Medicine (ACRM) and is a member of the Pediatric/Adolescent TBI task force of the Brain Injury Special Interest Group of

ACRM. She is an Editor-in-Chief for the American Speech-Language Hearing Association's (ASHA) journal *Perspectives* and is an Editorial Board Member for the *Journal of Head Trauma Rehabilitation*. Dr. Ciccio has an ongoing collaborative relationship with Dr. Lundine (above) with several co-authored papers and numerous shared presentations at national conventions.

Literature Review, Historical Perspectives in Ohio & Nationally, and Future Trends

TBI remains one of the most significant causes of morbidity and mortality for children across the United States (Centers for Disease Control and Prevention, 2018). Every year, thousands of Ohio children visit emergency departments with a TBI (Chen et al., 2017; The Ohio Brain Injury Program & The Brain Injury Advisory Committee, 2018). The chronic nature of a TBI and the potential negative impacts to long-term education, employment, health, and quality of life (Corrigan & Bogner, 2008; Corrigan & Hammond, 2013) pose a significant burden to public health and healthcare costs in the United States (Centers for Disease Control and Prevention, 2018). Although comprehensive follow-up after TBI is critical, research suggests that most children with TBI do not receive adequate care over time, with low rates of service utilization and high rates of unmet needs (Gerrard-Morris et al., 2009; Howarth et al., 2016; Slomine et al., 2006; Spaw et al., 2018b). Past studies found that parents and survivors of TBI report significant rates of unmet needs specifically related to cognitive and academic challenges following injury (Fuentes et al., 2018; Kingery et al., 2017; Kurowski et al., 2013).

Our own research has contributed to our understanding of these gaps in care provision in Ohio specifically. Our past work indicated that nearly 50% of children hospitalized at Nationwide Children's Hospital miss some or all of their scheduled follow-up appointments in the first two years after a TBI (Lever et al., 2019; Spaw et al., 2018b). Furthermore, the rates of therapy referrals for children with TBI who are admitted to two large children's hospitals in Ohio is very low (Ciccio et al., 2016), thus limiting children's access to therapy services after discharge. In a recent pilot study, a small number of caregivers and survivors of TBI, as well as medical professionals who work with these families, participated in semi-structured interviews. Themes identified in this work highlight gaps in Ohio's current continuum of care following TBI (Lundine et al., 2019). Specifically, caregivers and medical providers indicated that inconsistent recommendations often occurred when multiple medical providers were involved in a child's care. Caregivers and survivors emphasized that problems that emerge over time are associated with unique challenges. For instance, caregivers reported not knowing how or when to access specialty services, especially for newly identified needs. Along with a current project exploring predictors of long-term outcome and service utilization for children with TBI (Koterba et al., 2019), our collaborative body of work supports the need to close existing gaps in service utilization and access to care for survivors of TBI in Ohio. While emerging evidence identifies how gaps in care provision occur, no research is currently focusing on stakeholder-driven methods to mitigate these challenges.

To address this research-to-practice gap and improve rehabilitation care for TBI in Ohio, the proposed project will incorporate the perspectives of both caregivers and medical providers to develop recommendations for specific strategies that could target the needs of these key

stakeholders. The results of this study would create the foundation for a set of clinical recommendations or development of a prototype tool that could be trialed with a group of key stakeholders in a subsequent study. For example, we might learn that caregivers would like access to an online portal to connect them to a medical provider who could help answer questions as they arise, or that having appointments that are coordinated to reduce extra trips to the hospital would be helpful to families who struggle to take time off of work. Ultimately, the significance of this project is that key stakeholders will be included as active participants in the development of tools or strategies that aim to improve long-term care provision for children who sustain a TBI. However, we will not know what tools would be most helpful until talking with the people who will be directly impacted: caregivers of children with TBI and the medical providers who work with this population.

While the goal of this study was to involve participants from central and northeast Ohio, several barriers arose during the course of our project that limited our participants primarily to central Ohio. These barriers will be discussed subsequently. Nonetheless, findings from this study will have important and immediate implications for medical providers, researchers, and policy makers within the state of Ohio. Information gained in this study will allow us to develop and research clinical tools that will have the potential to improve long-term outcomes for the thousands of children and families affected by TBI in Ohio and nationally.

Financial Issues and Considerations

The initial year of our project was interrupted by the COVID-19 pandemic. As a result of challenges discussed in the subsequent sections, recruitment in Northeast Ohio was hampered,

leaving us with some unspent funds initially designated for recruitment of individuals and focus groups. Additionally, because pandemic-related restrictions required focus groups to occur remotely (via Zoom), no funds were required for these meetings. As a result of pandemic-related challenges, in May 2020, we required a 12-month no-cost extension for this project. This extension was approved, and during 2020-2021, we completed the work using our remaining funds.

Education and Training Issues and Considerations

There were no educational or training issues during this project. We have disseminated the preliminary results of Aim 1 of this project in several settings as listed below. Within the next year, we plan to further disseminate these results in both presentations and peer-reviewed journals.

Presentations

1. Haarbauer-Krupa, J., Beauchamp, M., & Lundine, J.P. (July, 2021). Traumatic brain injury in preschool children: The injury, symptoms, outcomes, and impact on family. Symposium presented at the International Brain Injury Association 14th Biennial World Congress on Brain Injury. Virtual Conference.
2. Lundine, J.P., & Bruns, K. (October, 2020). Engaging stakeholders to improve care for children with traumatic brain injury. Neuro-Trauma Research in Progress Seminar presented virtually by the Center for Brain & Spinal Cord Repair and Chronic Brain Injury Program, The Ohio State University, Columbus, OH.

3. Lundine, J.P., Ciccio, A., & Koterba, C. (October, 2020). Engaging stakeholders to improve care for children with traumatic brain injury. Symposium presented at the American College of Rehabilitation Medicine. (Virtual presentation due to COVID-19 pandemic)

Legislative and Regulatory Issues and Considerations

We had no difficulties obtaining approval from Nationwide Children’s Hospital (the Institutional Review Board of record for this project) or The Ohio State University (reliant IRB agreement) in fall 2019. Approval at our Northeast Ohio site, Case Western Reserve University (CWRU), proved to be somewhat more challenging. Due to staffing issues, the submission at CWRU took longer than anticipated, and was not ultimately approved until late winter 2020. In March 2020, Ohio shut-down universities, hospital- and university-based research human subjects research, and other related activities as a result of the COVID-19 pandemic. This caused several downstream effects to our project. Akron Children’s Hospital had agreed to serve as a recruitment site for our Northeast Ohio cohort; however, when the pandemic-shutdown began, recruitment was suddenly halted. In June, Akron Children’s informed our research group that it could no longer serve as a recruitment site for our study, limiting our potential recruitment significantly. At that point, Dr. Ciccio began the process of seeking approval from University Hospitals in Cleveland to recruit within their clinics, and she also contacted medical providers at the Cleveland Clinic Pediatric Rehabilitation Hospital. While both of these sites were open to dialogue and collaboration, the process of discussing the project, gaining verbal – and then official regulatory – approval took more than 9 months. Thus,

set-backs related to pandemic-related closures, in combination with a slower than anticipated initial start-up, made study set-up in Northeast Ohio less successful than planned.

In Central Ohio, researchers were able to continue remote/virtual recruitment and interviews with caregiver stakeholders into the summer of 2020 and did not face any particular challenges as a result of pandemic-related shut-downs. As COVID-restrictions persisted into the winter of 2020-2021, researchers submitted an amendment to the IRB to plan for virtual focus groups, instead of the planned, in-person group meetings. This amendment was approved in March 2021, and virtual focus groups were completed in April 2021.

Data and Information Issues and Considerations

As mentioned above, recruitment for the proposed Northeast Ohio cohort was challenged by several pandemic-related problems that limited our ability to recruit eligible families. Proposed enrollment was 30 caregivers and 6 focus groups. Planned recruitment in Central Ohio was for 15 caregivers. To attempt to increase our sample, we enrolled and interviewed 19 caregivers in Central Ohio. We completed 5 focus groups in Central Ohio, with a total of 29 participants. In Northeast Ohio, we interviewed 2 caregivers, and as a result of limited enrollment at this site, we did not complete focus groups for this limited sample.

While the results of our interviews and focus groups focus primarily on youth with more moderate to severe TBI, we believe the themes from this project are representative of many long-term challenges faced by families of children with TBI. We recognize that additional attention is needed to gather stakeholder input focusing on milder injuries, and our team will continue to pursue this work moving forward.

Preliminary Analysis of the Researchers' Findings

AIM 1: Identify the long-term needs of children with TBI and the tools and strategies that can be used to improve service provision for children with TBI from the caregivers' perspective.

Approach: During semi-structured interviews, caregivers will share their perspectives about their needs related to TBI care and generate ideas and recommendations for ways to improve care provision for survivors of TBI.

Caregiver Interviews: Inclusion criteria for this study were the following: 1) complicated-mild to severe TBI that occurred before the child's 18th birthday, 2) between the ages of 1 and 25 at the time of the interview, 3) injury occurred more than 6 months prior to the interview, and 4) caregiver was a conversational English speaker. Exclusion criteria were the following: 1) non-accidental mechanism of TBI, 2) pre-injury diagnosis of severe developmental delay, seizure disorder, psychiatric disorder, or other neurologic disease, or 3) brain injury that occurred during the perinatal period.

In Central Ohio, families who had children previously admitted to the inpatient rehabilitation unit at Nationwide Children's Hospital were invited to participate. Sixty-eight families were invited, and ultimately, 19 caregivers (100% mothers) agreed to participate in interviews. Table 1 shows demographic and injury-related descriptions of persons involved in interviews in Central Ohio.

Table 1. Demographic and Injury-Related Information for Central Ohio Cohort (n = 19)

	Years
Age at Interview	
Mean	16.0
Standard Deviation	3.2
Range	9.5-20.3
Age at Injury	
Mean	10.5
Standard Deviation	4.8
Range	2.7-18.1
Time Since Injury	
Mean	5.2
Standard Deviation	2.9
Range	1.2-9.6
Estimated Median Family Income	
Mean	61,894
Standard Deviation	23,310
Range	20,978-123,618
Total Length of Stay	Days
Mean	53.5
Standard Deviation	32.9
Range	13-111
Sex	n (%)
Female	2 (10)
Severity of Injury	
Severe (GCS 3-8)	16 (84)
Moderate (GCS 9-12)	2 (10.5)
Mild Complicated (GCS 13-15 with evidence of intra-cranial lesion/bleed)	1 (5.3)
Mechanism of Injury	
MVA	12 (63.2)
Struck by object	5 (26.3)
Fall	2 (10.5)

In Northeast Ohio, 2 families were recruited via social media. One participant, a 9-year-old, was 1-year post-mild TBI. The other participant from Northeast Ohio sustained a severe TBI when he was 10 years old, 2 years prior his interview.

All caregivers participated in remote semi-structured interviews. Research assistants asked caregivers to first share about their child, their injury, and hospitalization. The semi-structured interview continued with prompts to elicit the caregivers' perspectives on key areas of care such as preparation to return home from the hospital and back to school, experience with the health care system, training and education provided to them about their child's injury, recommendations that might have improved their experiences, any situations that have arisen where the family did not know to whom they should ask for help or how to get help, any services they received after discharge, challenges not addressed, positive experiences, and any changes they would make about the time since their child's injury. Research assistants also asked families questions from the *Child & Adolescent Scale of Environment* (CASE; Bedell, 2011). Caregivers were read a list of possible problems their child may be experiencing with the physical or social aspects of the home and other places in the community OR with the quality or availability of services or assistance that he or she needs. Caregivers were asked to rate each aspect as "no problem," "little problem," "big problem," or "not applicable." For example, caregivers were asked about any lack of support and encouragement for their child in the community or neighborhood and inadequate or lack of programs and services at school.

Interviews were transcribed by trained research assistants and uploaded into NVivo (NVivo 12, released March 2020), a software designed for qualitative data analysis. Two trained research assistants independently coded every interview using NVivo, a qualitative data analysis software. Coders compared any discrepancies in themes until consensus was reached. A third, independent, reviewer then reviewed the initial consensus coding and made suggestions and comments. Using an iterative process, researchers discussed the themes, arranging and organizing participant quotes until overall consensus was reached and final themes were agreed upon.

Caregiver-Generated Interview Themes: Caregiver comments fell into the following six themes: 1) hospital-related experiences, 2) home life and family dynamics, 3) counseling, 4) school and educational experiences, 5) life in the community and public knowledge of TBI, and 6) physical and emotional changes in the child. In general, caregivers spoke about more barriers or negative aspects of their experiences compared to facilitators (see Figure 1).

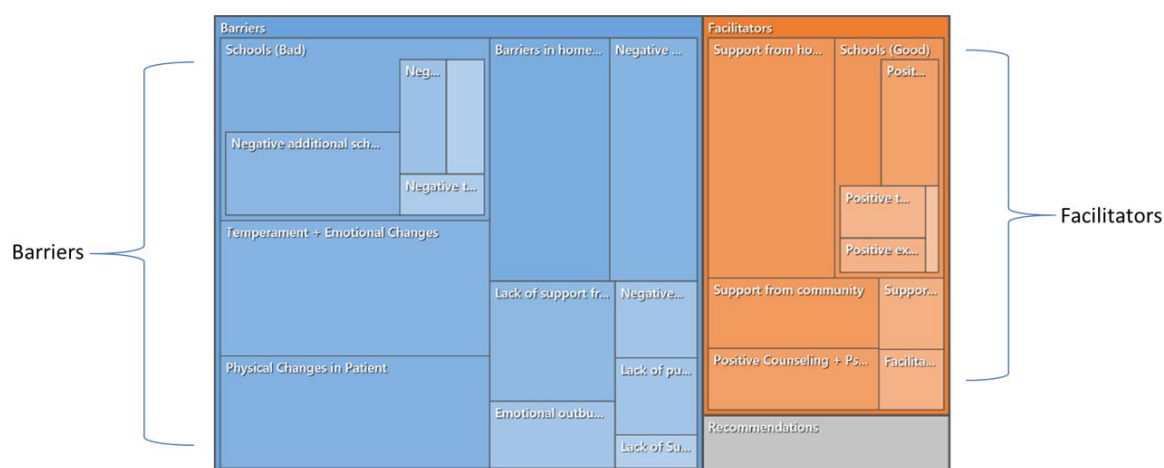


Figure 1. General breakdown of themes from caregiver interviews.

- 1) Hospital-related experiences: Caregivers spoke about their time in the hospital and shared examples of both positive and negative experiences. Caregivers spoke of positive hospital-related experiences such as the following:

- *I felt like they **gave us a wealth of information** about what to expect and you know, just what going home would look like.*
- *When I had to order the diapers and the certain medical supplies that he needed and the Pediasure, they called three months in advance, so **I didn't have to worry about it for 3 months after he got out of the hospital.***
- *Even after I came home **the social worker and the doctor really did talk to me** and look out for me at that time.*
- *I got **a lot of education on the brain injury** so I knew like the issues that could happen or the ones that he was having, so I felt prepared in that sense, at that time.*
- *Even the therapist and doctors and nurses everyone has their bad days and it just amazed that when they were there in his presence, **they could have had a bad day or maybe that they didn't want to go to work that day but they never showed it.***
- *They actually **cared about** not only the child, but **the family as a whole.***

Some negative experiences they shared included the following:

- *I don't know who at the hospital looks up local resources **but if they could look up in the person's area like here are some pediatric doctors that***

- specialize in brain injury.** Even if it's typed up or in a pamphlet just a list of things that could possibly help you out in the event that you would need one.
- *I think finding out information on therapists and treatment that's not provided by the hospital is difficult and any parent put in this situation is put in a very vulnerable position because **suddenly you'll find people that will make amazing claims if you do this and you pay this amount then we're gonna get an amazing recovery.***
 - *And I remember just breaking down in tears after that because **I felt like they [hospital] didn't know how to handle it.** And I was just trying to keep him safe and he was wailing around and were on this neuro floor and the doctor would come in and tell me to keep the room quiet because he has a TBI, that was when they were doing the construction in the hospital. So they were doing construction, like pounding outside his window all day long and they kept telling me to keep the room quiet. So the neuro floor needed more education at that point?*
 - ***It would've been nice** for me to have had **someone** that could've **came here maybe to work with me in my home environment to teach me a little bit***
 - *A lot of the **therapies** they would let you come but it was more just to watch, I think it **needs to be more hands on.***
 - *So when you leave the hospital it would be beneficial to already **know if they have this problem these are the people you need to go to.***
 - ***I didn't feel prepared** to handle all the stuff after the hospital.*

- *They were also throwing everything on me at once you know and trying to comprehend everything while all this stuff's going on with your kid. **It was too much overload.** So I mixed up a lot of stuff over the years.*
- *We get our discharge summary and then they have the big conference call with **Medical_Providers_Name** and the psychologist and neuropsych and all of them they were on the initial IEP meeting with their recommendations but then it's like **everything after that is up to us***
- *Because when you're inpatient you're treated amazing, but I think that **there's a disconnect for the outpatient clinics.** I mean, just to continue her therapy we waited forever to get orders and changes and **no one calls you back for weeks on end and it's frustrating.***
- ***You may have said something a week ago but I didn't hear you because my kid was on a vent** we didn't know if she was gonna live. So, I feel like it's hard because everyone throws themselves at you but then that's it, they never come back. And so then it's like oh maybe I remember that, maybe I don't, I don't know. **It's just, you're kind of in a fog at that point and you don't really, you don't hear anybody.***

2) Home life and family dynamics: Caregivers spoke about their experiences

bringing home their child with TBI and how family dynamics shifted as a result.

They spoke of positive changes within their families:

- *I guess I just have to give myself props because somehow **I just kept going and feeling confident about it.***

- *I'm rather lucky that I work for a small company and **they continued to pay me while I was off work.***
- ***He had his parents behind him.** Pushing him, fighting back with tough love and through tears. Being his advocate and never giving up and never settling. Keep on pushing and having faith.*

They also spoke of challenges facing their families.

- ***I wasn't prepared for was how busy life was when we got home.** You're used to—everybody's coming to you at the hospital: all your therapies, every doctor, everything you need, they come to you. And so then **you got home and it was like "wow..."***
- ***I think maybe I wasn't prepared for it until later and I've read a lot about now is kind of a grieving process.***
- *When you get home you're doing it the whole time but **you also have other responsibilities at home too.***
- ***Momma can't pay close attention to you 24 hours** like the nurses did.*
- ***I don't always have the resources** that I need.*
- *I learned that **the stuff there is to do costs too much.** When I was in the hospital with him they said you can't go back to work. He gotta have 24 hour care.*

- ***Pretty much everything fell on my shoulders and one person dealing with that is a lot.*** You're dealing with the trauma as well as trying to make sure he gets everything that he needs in school, out of school, and in the community

3) Counseling and mental health support: Caregivers spoke about the need to identify appropriate mental health or psychological support services for themselves, their child with a TBI, and their other children. Some caregivers spoke about the positive experiences they have had when connecting with these services.

- ***Nobody ever gave us, you know, a false hope, or like I said, through the whole process they were very matter-of-fact about this is where we are, this is where we hope to be, but we'll again just take one day at a time one moment at a time.***
- ***But I mean, they did great with explaining and telling me even after asking all those questions, that 24 hours. They also said if you need help, we're a call away. They were always there no matter what.***
- ****Childs_Name* had a really good psychologist when he was in the hospital, and y'know he kind of bonded with her.***
- ***Only services that he really receives that is supportive is the psychiatrist and the psychologist. Where he's able to express his emotions and how he feels at the time. They're always available when they need him to be.***
- ***The hospital was really good at preparing me for what to look for so I felt like I knew what to look in his behaviors.***

- *I like how **they worked with me** not only for his injury, but as well **as my own anxieties and stuff.***

Caregivers also spoke about the challenges in identifying service providers and having the appropriate support to assist their family's mental health in the time since their child's TBI.

- *Yeah [there were psychosocial challenges that were not addressed], I wish he would've had some kind of like therapy or counseling while he was in the hospital. Because that was a lot for him to go through, and it was pretty much focused on him being able to get up, being able to walk and all that kind of stuff, **but it was not focused on his actual mental well-being.***
- *Because **that paperwork they give you**, it's not enough information for me. Like it fills you with too much information, but **it ain't the information that you're looking for.***
- *They're not things you generally research before you're thrown into it very quickly and unfortunately the outcome of your recovery is really based on how much knowledge you have and how much you can do for that patient. **Then a lot of the responsibility is then on the caregiver I think that's a very difficult situation.***
- ***It should be some kind of outlet for parents** as well, to help you because you're too busy trying to get things done that you can't actually process what's going on.*

- *Actually went in to see the **psychiatrist** that he was supposed to see, **the doctor literally said that he didn't have any brain injury or anything like that because he acted normal.***
- *I think **there needs to be a little bit more attention to the mental health of particularly a teenager who's just experienced an injury** and they, y'know he's trying to adjust to a different kind of normal for him, not to mention the fact that the depression and everything that goes along with just the brain injury itself.*
- *Cause I mean it took me **six months to find him a psychiatrist** and that was me looking on my own.*

4) School and educational experiences: Caregivers spoke about their experiences transitioning their children with TBI back into school and maintaining appropriate services for them even many years after their injury. Examples of positive experiences shared by caregivers included:

- *So the biggest thing was **routine, routine, routine.** *School_Name* did it great. By the time he was finished with *School_Name* he went to *School_Name* which I loved.*
- *At school I'm **really glad that the school recognized** he needs extra help.*
- *I can't really think of anything further they could've done because **they worked with me every step of the way.***
- *Yep, **very lucky** we found a very **supportive school district.***

- It actually **went very smoothly** it was very gradual. **It was very gradual** and I think that helped. But the **support through the school system has been unbelievable.**
- Yep, he's on an IEP and then if he needs any extra help there's people to step in. **They cut him a lot of slack I will say that.** When he gets in trouble he don't get in a whole lot of trouble. He gets less time in school. Which he loves so it works out.

Some challenges described by caregivers included:

- They're dumb as heck when it comes to his injury. I don't **even think they understand the extent** of him being in XX(unintelligible). Sometimes I feel like they **throw him out to the wolves and leave him out to fend for himself.**
- **These schools they don't care for real.** And like when I'm having these issues, I don't know who to talk to.
- He was like, "Mom they got in me in this class and I feel like I'm around a bunch of slow kids. Nobody can talk, I'm the only one that can talk, they can't get up and do their work. They have to have somebody with them at all times, **why can't I be in a regular class? I'm a regular kid. I can't even relate to none of these kids.** They can't give me a high five, I can't sit in the class and play games with them, they just sit here!"
- Because in my area, I don't know about the bigger cities, **they don't know a lot about brain injury** so you're **fighting with the school all the time.**

- *I needed a person to look at me and say, “yes, I really think this is the best thing” or “no, I don’t think this is the best thing,” and I felt a little inadequate, and I’ve never done this before! **I just wasn’t sure what to do in that situation.** And on one hand you felt good because they’re telling you, “hey, we think your kid’s doing great, and we don’t feel like he needs specially-designed instruction,” but on the flipside, it’s like I want my child to be protected going into college to know that he’s got, you know, everything he needs. **He’s already got enough mountains to climb, I don’t want to make it harder on him.***
- *To be honest with you I thought the school would have helped better. I thought that they would have to deal with more things than what they did. And to be honest with you they didn’t.*
- *There is not enough resources for people with traumatic brain injuries nor is there enough education. I feel like they have a school for the blind, they have a school for the deaf they have **all type of schools for people and kids with disabilities but when it comes to traumatic brain injuries I feel like they throw them out to the wolves.** They put them back into these regular schools, public schools that they attended before their injury. They throw them out to the wolves. **There are no resources. The schools are not educated enough. They do not take it serious enough either.***

5) Life in the community and public knowledge of TBI: Caregivers spoke about their experiences navigating the community after their child sustained a TBI. Some positive experiences caregivers discussed included:

- *People were really good about giving us their card and you know saying, **“if you need anything, reach out to us,”***
- *I think they did a great job in helping us to **learn to celebrate all**, even if they might’ve been tiny, but they were victories, and to see them that way. They kept me very focused on the here and now, in this moment right now, not looking too far ahead, ever. Which was good, you needed to learn that in that time and I think with a TBI, that’s something that people have to really learn is, **you have to live in the moment.***
- *I’m learning about this stuff because I follow a bunch of **TBI groups on social media**. I’m able to communicate with other people that actually have it. That’s how **I was better able to understand my son.***
- ***My job was very supportive** of me going back and forth and stuff.*

Caregivers also discussed barriers they experienced in their communities.

- *The **disability** board you have to have certain amount of disability to be there and *Child’s_name* been **denied three times**. Once he came out of the hospital he was denied. He wasn’t disabled enough. Okay. **The kid is in a wheelchair, the kid can’t walk, talk, the kid can’t feed himself, can’t clothe himself, what disability does he have to have to have for you***

guys to become a part of his life? They said well he'll be able to learn this stuff as he gets older.

- *I have been **searching since the accident for other parents** who have kids who have a brain injury just so I have a **support group of people** that are experiencing the same things, and I **have not found any***
- *There's **not a lot of resources around here for brain injuries.***

6) Physical and emotional changes in the child: Caregivers spoke about the physical and emotional changes in their child following a TBI.

- *So they tried to not break his routine. Because **if you break his routine, frustration.***
- *He was **frustrated**, and that's to be expected. Cause you're trying to do something that you already knew how to do, over.*
- *He knows he's different from the other kids, **but he tries to fit in with crowds that he shouldn't**; because the part of his brain that was hit was you know, was that part that tells him right from bad.*
- *He knows how to work and knows the working thing, he can clothe himself, he knows how to cook, laundry, clean, he knows all that stuff. But when it comes to **finances**? He doesn't understand that. When it comes to his **medical**? **He doesn't understand that.***
- *I had high hopes for him when he was younger. Now **I don't even think he can live on his own right away.***

- But his **impulsiveness** I feel like **it could have him** in a lot of trouble, like a **world of trouble** in the near future so I **don't let him out of my sight**.
- **The worst is him adjusting to the disability.** Especially because he was athletic and he was very popular. He is an outdoor kind of kid. So to take that all away from him, he sits in his room and cries sometimes because he can't play football anymore, can't wrestle, he can't do anything he did before.
- But it's like the part of your brain that teaches you **discipline**, my son's is **gone**.
- Of course he is different. He used to be more reserved more to himself and things like that as far as his feelings. Now it's like if something happens **boom he gets an instant attitude**. It's like **he ready to fight everyone in the world**. That's the difference between him he never was about when he gets angry wanting to fight and wanting to cuss and lash out and things like that.
- His **demeanor is totally different**, like he has anxiety and he's had it since the injury, like he's afraid of the dark, he has some **fears** that are unrealistic. He's scared to be alone, he gets **angry** real easy, he definitely has had some **behavior changes** since the injury. And **I don't really know how to fix it**, I just try my best everyday to do what I can, but I know...I guess this is the part just kind of where it makes me sad.

Examples of each theme were reviewed by the lead investigators who then determined which themes and supporting quotations would be most appropriate to include in focus groups with medical professionals and educators. Themes that were included for the focus group included those that could be addressed by the stakeholders that were included in the groups: 1) hospital-related experiences, 2) transitioning to home, 3) counseling, mental health needs and physical/emotional changes, and 3) school/educational experiences.

AIM 2: Identify the tools and strategies that can be used to improve service provision for children with TBI from the perspective of medical providers, based on themes identified during caregiver interviews.

Approach: Medical providers with knowledge of the current system of care will share their perspectives on long-term needs related to TBI service provision and incorporate suggestions provided by caregivers to identify strategies that would improve care delivery for survivors of TBI.

Focus Group Participants: Researchers held 5 focus groups in spring 2021. As described previously, due to limitations in recruitment in Northeast Ohio, focus group participants were solely recruited from Central Ohio to complement the caregivers recruited in Aim 1. Twenty-nine medical providers and educators participated in these groups. See Table 2 for professional and demographic details of focus group participants. Participants represented the following professions: speech-language

pathologist (n=2), occupational therapist (n=2), physical therapist (n=2), child life specialist (n=1), therapeutic recreation specialist (n=1), rehabilitation case manager (n=1), social worker (n=1), nurse (n=4), nurse practitioner (n=1), school psychologist (n=2), hospital-based teacher (n=2), clinical psychologist (n=3), neuropsychologist (n=1), and physician (physiatrist, surgeon, neurosurgeon; n=6).

Table 2. Demographic and Professional Information for 29 Focus Group Participants

	Average (Standard deviation)	Range
Sex (Female)	79%	
Age	42.4 (8.9)	30 - 61
Years Practicing	14.5 (10.7)	.5 - 38
Years Working with Pediatric TBI	13.3 (9.1)	1.5 - 35
Highest Level of Education		
Bachelor's Degree	20.1%	
Master's Degree	31.0%	
Professional Degree (e.g., M.D., OTD)	31.0%	
Doctoral Degree (PhD)	17.2%	

Due to pandemic-related precautions, all focus groups were held virtually over Zoom. Each focus group lasted approximately 60-minutes and included 4 to 8 participants. Drs. Lundine and Koterba moderated each group. Focus groups included a brief introduction of the study that included a description of the aims and participant demographics from Aim 1. The following themes, identified as part of Aim 1, were

described with sample quotations shared in a presentation to illustrate the perspectives of caregivers on the given theme and to elicit discussion amongst group members. The sections included the following themes: 1) hospital-related experiences, 2) transitioning to home, 3) counseling, mental health needs and physical/emotional changes, and 3) school/educational experiences. Moderators asked open-ended questions to elicit the participant's thoughts about caregiver perspectives. For example, when discussing home-going transitions, the moderator offered a brief summary of the quotations from caregivers and then included the following discussion prompts:

Some caregivers shared that they experienced difficulties related to the transition from hospital to home or finding resources in their own community. As a team, we view discharge as an ongoing process, but it doesn't seem like all families are experiencing it in the same way. What are some ways that we could re-imagine the discharge process to make families feel more prepared to go home? [discussion] How do we assess the challenges/barriers that families might face when they go home? What do you see as possible opportunities here? [discussion] Based on the quotes that we shared, what other ideas do you have surrounding this topic? [discussion]

Participants engaged in approximately 10-minutes of discussion per theme, and then researchers concluded the focus group meeting with a broad question asking the participants *"If resources weren't an issue and you were in charge, what would be your ideal approach to delivering health care to children with TBI and their families?"*

Participants were offered the opportunity to share any last thoughts before the group was concluded.

Focus Group Themes: From discussions with medical and educational care providers, researchers identified the following three strategies consistently, across focus groups, in response to caregiver-related experiences: 1) need for improved education to parents during hospital admission, 2) need for a care coordinator for long-term assistance to families and survivors, and 3) need for improved mental health support for families and survivors.

1) Need for improved education to parents during hospital admission: Medical professionals recognized that caregivers often receive different messages from different providers, making it difficult for caregivers to understand the likely prognosis for their child. Neurosurgeon stated:

I would say that one of the biggest difficulties you're running into is communication with families in terms of families getting different messages from different providers and that can just run along the spectrum, and so I mean it's one of those things we're kind of battling with in most of these cases.

Physicians commented on not having good, objective data on which to base a prognosis, and the challenge in telling families "we really don't have a good idea of which way this is going." Surgeon commented:

You can get mixed messages of what recovery is going to look like, and you know, think about it from my mouth, but from an educational institution as well,

right, so you have everyone from medical students, all the way up to interns, residents, fellows and attendings that can give mixed messages.

There were several ideas discussed as potential solutions to address this breakdown including: case conferences with family and multiple involved disciplines, using a teach-back or more visual methods (e.g., checklists, written information) of education to ensure families have access to and/or understand the information they are being told, and being more explicit with intentions for services like rehabilitation, when we expect families will be more engaged so that they feel prepared to take their child home. For example, Inpatient RN said:

Almost from the very introduction, the first time you're establishing care of saying you know, while I'm here, and while I'm working with your child, I would like you to be part of therapies and actually do things with me in order to learn it because, even if this isn't what you're doing when you're going home if you start now we'll continue to grow ...

Another important point of consideration was to ensure medical professionals are considering where the family is in their grief process and how receptive they are to education. Child Life Specialist stated:

I guess kind of what came to my mind was thinking just about the grief process and what they're going through, knowing that their cognition is lower, and their anxieties higher with all of this, so I'm just kind of curious to how we could look at that, in a different way, as well, of like when are they ready for that information and maybe it doesn't feel as ongoing because, um you know I think

they're still processing that even the denial of like, well that's not going to be my kid they're going to come back to the normal, because it is so unpredictable.

A related point discussed by participants was improving the ability to plan for discharge by improving communication with families and attempting to improve the availability for home-visits prior to discharge. Participants discussed that home visits were eliminated during the COVID-19 pandemic, which means that families were not able to take their children home before discharge to explore any barriers that might arise and clinicians were not able to visit homes to assess for safety or mobility issues. Focus group participants discussed, as pandemic-related restrictions begin to ease, reinstituting these visits is important to help families feel prepared to return home with their child. Participants also discussed that clinicians can do a better job of talking with families about potential barriers they might face at home, including social and financial barriers, that might pose challenges to safety and family functioning. Inpatient Rehabilitation staff discussed that the “24-hour care” routine, where parents are expected to care for their child for a full 24-hour period before discharge is likely not a sufficient practice to prepare them to go home. Discharge Planner stated:

I don't because I don't even know that 24-hour care perfectly prepares them fully for the extent of it that's I think that is a huge barrier, ...[because]... I just think it's so different when it's home versus when it's [at the hospital].

- 2) Need for a care coordinator for long-term assistance to families and survivors: In response to many of the barriers described by parents, both medical professionals

and educators stated that having one person to help connect families to resources and answer questions that arise after they leave the hospital would be a “game changer.” Repeatedly, focus group participants spoke about the idea of having a care coordinator who is knowledgeable about TBI in youth, understands both the medical and educational systems, and what resources are available within the community.

School Psychologist 1 stated:

It seems overwhelming, at times, and you know some do better than others, but I think that's where it falls apart at least what I see after they leave the hospital.

Surgeon suggested that a care coordinator would be:

...Essentially an RN or a social worker that's specifically you know, designed to help the families again just navigate their pathway post-discharge because we all know how complex, it is.

Inpatient RN emphasized this point:

The care coordination was definitely, when you think about it, that is, the thing that these patients really need is that continuous kind of help and that continuous advocate really, what it is, advocacy throughout the entire process, who becomes a wealth of knowledge and a wealth of resources and a wealth of support.

Several individuals indicated that a care coordinator, or liaison, would be the one thing they would implement to support youth with TBI if resources were not an issue. School Psychologist 2 stated:

I'd give him a case worker who was like the person to be the you know, the main contact liaison between them and the hospital, regardless of what you know department, and I would have home visits and or you know set up transportation for them... And maybe even that liaison would be like a liaison between the home and the school as well.

Outpatient RN 2 added:

I'm kind of on the same page I would give them a liaison, a person, their person, that would be able to be in the home checking on them, be able to you know coordinate things, help explain things set them up for community resources and take the burden off of trying to figure it all out and let the family focus on healing and being a family.

Importantly, focus group participants discussed that a care coordinator or liaison could help to support children with TBI in their educational pathway as well. As discussed above, caregivers spoke about the challenges their children faced when returning to school, stating that schools needed additional education related to TBI.

The Hospital School Teacher shared that a care coordinator could be:

part of the discharge meeting if they can be and then parents know that they have a contact person who can go to the IEP meetings with them can be there, should they have continued questions with school that's not within my role as the rehab teacher, because there is not enough time to be able to do that and to expand in that way, but if we did have somebody who could join us towards the end of this say and take on that role, and then be that constant person who can

continue to have conversations with the school, I think that would be maybe, something that we could consider for in the future.

School Psychologist 1 also mentioned that another use of a care coordinator could be to help educate school systems:

But if that could be taken to other school systems, you know and model that where there was somebody whether that's from the hospital setting or state level or wherever, to do that kind of general understanding, the training of traumatic brain injury, and that transition here (to school) and why it's so important to be involved from, you know the hospital end to the transition back to school piece, and then everything that goes along with that. ... That education piece is huge.

- 3) Need for improved mental health support for families and survivors: Medical providers and educational personnel also spoke about the clear need to improve mental health support to not only survivors of TBI but their parents and siblings as well. Medical professionals recognized time as a significant barrier to addressing counseling and mental health of patients and families while they are in the hospital but also the timing of counseling during the inpatient stay:

I think, having the time for every different staff person to kind of really sit down and listen can be really challenging because, at least for therapies we're so very focused on like the patient and what we need to get done. But then I can also see there being a barrier of kids not being ready to like open up and share at this point, maybe kind of not getting out of it, what they what they need.

A Recreation Therapist stated:

Yeah and I can see them, like they've got so much support while they're in the hospital they're not having those kind of issues until they go home and then they're exposed to their friends and the pressures of school and all those other you know pressures and responsibilities that they're going to have to take on after they leave the hospital that that maybe they don't realize that they're ... experiencing difficulties until they're, till they leave.

A Child Life Specialist offered a similar sentiment:

They almost need that adjustment period and that support soon after discharge for those more difficult times.

A Clinical Psychologist talked about the challenges with the lack of available professionals in her field who are experienced in pediatric TBI, making it challenging for youth and their families to find appropriate service providers. Several providers discussed that due to online use of Zoom and other virtual platforms during the COVID-19 pandemic, perhaps virtual support groups would be a reasonable and successful way to offer mental health support to survivors of TBI and their family members. Offering services in a group setting would also maximize use of medical professionals like social workers, child life specialists, and psychologists, allowing them to provide services to multiple persons simultaneously. The Rehab Social Worker shared:

My personal barriers just covering a lot – it's just it's a lot – I'm having a hard time kind of keeping up with my workload, as is, and to add another thing it's kind of

difficult. It's just difficult. That's my personal barrier, I think, I do I think if I had a consistent person who can help out with running a group I'm all for it.

The Rehab Social Worker also added:

Because coming from the outpatient road if you decide you want psychology is a very long wait, longer for psychiatry like nine months for psychiatry and six months for psychology.

A Rehab Physician also added:

I think that a lot of families feel like they're in a bubble there all alone... [with additional resources I would offer] a group that meets every so often just some exposure to different families and they can kind of build upon each other, like hey, this is what we do to help out our child. And you know these are some tips that you can do. I'm just thinking like exposure, you know those who have been where you know, a child with TBI is trying to get through, I think that there's something else I would do just helping families have more exposure.

Conclusions

There are some limitations that should be considered as researchers and clinicians move this work forward. The population of children included in this study focuses primarily on those with moderate-to-severe TBI, and those who were admitted to an inpatient rehabilitation unit. For children with TBI, this represents a minority of the total population. The future directions identified in this study do however have cross-over applicability to youth with TBI and their families more generally. Children who are not admitted to inpatient rehabilitation would also

likely benefit from a care coordinator, for example, that could help connect the family to resources if or when issues arise in the future. A second limitation to the population included in this study is that caregiver interviews included families with primarily male children. While males do experience more TBIs than females, the ratio tends to be closer to 60/40, whereas our population was 80/20 male to female. It is important for future work to ensure that female children and adolescents do not experience different barriers following a TBI, or that strategies identified as potential solutions in this study address challenges faced by families with female children with TBI as well as males. While this study aimed to recruit children from two urban centers in Ohio, pandemic-related difficulties made this impossible within the designated study period. Larger, multi-site studies should continue to address this goal to ensure that the needs of all Ohio children with TBI are being addressed.

Funding from the Ohio Department of Public Safety allowed us to gather important stakeholder perspectives that give clear direction for future prospective research projects to improve the continuum of care for children with moderate-to-severe TBI and their families. Caregivers of Ohio children, who were on average 5 years post-TBI, identified several specific areas that could improve the long-term care for these individuals and their families and medical providers and educators incorporated caregiver perspectives into several interventions that could be implemented in future clinical and research projects (Table 3).

Table 3. Stakeholder Themes and Actionable Items

Caregiver Theme	Focus Group Response	Potential Actionable Solutions
Hospital-related experiences and transitioning to home	Need for improved education to parents during hospital admission and to prepare them for discharge	Streamline education to ensure families receive consistent information; Consider barriers to discharge and those present in their home environment & social situation post-discharge; Consider virtual modalities to complete home evaluations
School/educational experiences	Need for improved care coordination to provide long-term assistance to families and survivors	Consider creation of TBI-specific care coordinator who helps manage services, resources in medical & educational realms
Counseling, mental health needs and physical/emotional changes	Need for improved mental health support for families and survivors	Consider virtual support groups for survivors, siblings, and caregivers

Recommendations

As we continue the analysis of these interviews and focus groups, themes identified from this work will be shared with all stakeholders to allow their input to shape future recommendations. Future work that considers the findings from this study will help to improve the long-term outcomes of children with TBI in Ohio and beyond. This study resulted in actionable suggestions that lay the groundwork for concrete next steps and future research.

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