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Putting the person in person-centered care: Stakeholder experiences in pediatric traumatic brain injury

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Abstract.

PURPOSE: This pilot study sought to describe the perspectives and experiences of survivors of pediatric traumatic brain injury (pTBI), their caregivers, and the medical professionals who serve them.

METHODS: Thirteen people participated in semi-structured interviews: five survivors of pTBI, their primary caregivers, and three medical professionals who work with persons who have sustained pTBI. The study involved a prospective, qualitative, participatory action research model with convenience sampling. All interviews were transcribed and thematic analysis identified central concepts within and between groups. Additionally, the Consolidated Criteria for Reporting Qualitative Research (COREQ) were applied.

RESULTS: This study found that survivors of pTBI and their caregivers commonly noted later developing issues, social challenges, and difficulty in post-rehabilitation transitions. In addition, both caregivers and medical professionals reported the need for improved follow-up with survivors, evidence-based research, and medical and therapy providers with specific training on pTBI.

CONCLUSIONS: The perspectives provided by key stakeholders in this pilot study identify common themes that should be central to driving innovation in rehabilitation research and clinical care.

Keywords: Children, adolescents, healthcare, rehabilitation, traumatic brain injury

1. Introduction

Traumatic brain injury (TBI) is widely accepted as the leading cause of acquired disability for children in the United States [1,2]. An estimated 29,000 new children in the US each year demonstrate persistent and significant changes in social, behavioural, cognitive, and physical functioning following a TBI [3–5]. These

persistent changes are associated with difficulties in long-term health, engagement in functional community roles, and integration into society [6,7]. In addition, research now suggests that sequelae of TBI may represent a chronic, continually evolving disease process rather than simply an acute injury that resolves over the short-term [8–10]. This is especially concerning for individuals injured during childhood and adolescence given that these survivors must manage the long-term impact of their TBI over the course of their lifespan.

Gaps in identification and service utilization show that our current system of care is not sufficiently work-

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ing for children who sustain TBIs, thus diminishing the likelihood of long-term health and function for these individuals [10,11]. Past studies have shown under-identification of children and adolescents admitted to the hospital with TBI and/or that these patients and families are not linked with appropriate services when they are hospitalized [12–14]. Additionally, families do not consistently return for recommended follow-up visits following an admission for pediatric TBI (pTBI [15]). Further studies have identified under-utilization of support services that can help to promote health and function for children and adolescents with TBI and their families, particularly in the chronic stages of injury [16–21]. Children with TBI are also dramatically under-identified in our school systems [10,21,22]. Current literature indicates that less than half of students who have survived a pTBI are receiving educational supports [22–25].

Additionally, for medical professionals who care for children and adolescents with TBI, evidence-based practice guidelines are limited [26–28] and inclusion of key stakeholders to develop intervention and research priorities is uncommon [29–37]. A group of papers from Roscigno and colleagues [30–32] described an ethnographic study that collected data from survivors of pTBI and their parents. These semi-structured interviews identified themes related to survivor experiences, perceptions, and quality-of-life, and they demonstrated that children as young as 8-years-old can share experiences related to their TBI [34]. Roscigno et al. also collected and described parent perceptions related to school reintegration [31], changes to the family unit [30], and medical professional-parent communication [32]. Roscigno and colleagues concluded that extensions of their work were needed that included the experiences of children injured at younger ages, perceptions of recovery and needs further-post injury, larger samples, and medical professionals as key stakeholders. This important body of work established a foundation for stakeholder-driven research related to pTBI.

When individuals do not receive appropriate rehabilitation services post-injury and experience barriers that prevent their adherence with rehabilitation recommendations, the long-term health and function for those survivors could be negatively impacted [38]. Due to the fact that the voices of survivors of pTBI and their families are rarely heard in the literature [30–33,35–37,39], we are not able to account for the most ecologically valid, stakeholder-driven needs related to long-term rehabilitation following pTBI. The perspectives of key

stakeholders will help to define the most salient factors related to medical management and rehabilitation, identify where gaps exist in service provision, and ensure that these perspectives inform future clinical research. As a result, the negative impact to overall quality-of-life caused by a pTBI may be minimized. The theory driving this research is consistent with the recommended shift in focus from impairment-based dysfunction to participation-focused intervention [40]. Currently, this perspective is largely missing from the overall approach to pTBI rehabilitation [41,42].

The objective of the current study was to collect pilot data to inform a more comprehensive look at the perspectives and experiences of key stakeholders related to pTBI (survivors, their caregivers, and medical professionals) in order to examine areas for innovation in research and clinical service delivery. Researchers were interested in understanding the perspectives of these key stakeholders as related to their experiences surrounding pTBI. The objectives motivating this study were to:

1. Describe the perceptions of caregivers and survivors of pTBI based on experiences since the time of the injury.
2. Describe the perceptions of medical professionals who work with the survivors of pTBI.

2. Methods

This exploratory study primarily used a qualitative, participatory action research model with convenience sampling. The methods reported are consistent with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [43].

2.1. Participants

Approval from the Institutional Review Board was obtained before any research activities were conducted. To recruit survivors and caregivers, five families that include a child with TBI and had previously expressed interest in research activities were contacted via phone to participate. The first author provided survivors and their families with information regarding the purpose of the study and clearly stated the interests of the researchers. All participants agreed to be included in the study, and therefore recruitment did not yield non-participants. All persons signed the appropriate consent/assent forms prior to participation.

Table 1
Demographic and injury data for survivors and caregivers

Survivor	Age at injury (years)	Years post-injury	Severity of injury	Length of hospital stay (days)	Caregiver interviewed
S1	17	4.5	Severe	53	Mother (C1)
S2	4	5.5	Severe	54	Mother (C2)
S3	17	10.5	Severe	~95	Step-Mother (C3)
S4	15	7.5	Severe	121	Mother (C4)
S5	10	3.75	Severe	107	Father (C5)

Table 2
Medical professional history

Medical professional discipline	Total years practicing	Years practicing in pTBI
Speech-language pathology (SLP)	13	11
Therapeutic recreation (TR)	12	11
Nursing (RN)	17	14

To be included, the survivors of pTBI were between the ages of 7 and 25-years old at the time of enrollment, had a diagnosis of moderate-to-severe TBI that required hospitalization of at least one night, and were injured between the ages of 1 and 18 years. Hospital admissions for all five participants included inpatient rehabilitation. To be included, a caregiver had to have been actively involved throughout the recovery and rehabilitation process for the survivor (see Table 1 for demographic information for all survivors and caregivers).

To recruit medical professionals with specialty in pTBI, the pediatric rehabilitation team at a large pediatric hospital was contacted about the opportunity to be interviewed for this study. The first three medical professionals who responded were included. Medical professionals were required to provide assessment and/or treatment for survivors of pTBI as part of their clinical responsibilities within the last year. A speech-language pathologist, recreational therapist, and registered nurse were included in this study (see Table 2).

2.2. Semi-structured interviews

The semi-structured interview format used in this study consisted of open-ended questions, probes, and follow-up questions (see Table 3), which ensured the interview was driven by the participants' experiences and not biased by the researcher [44,45]. The interviews were designed to examine participants' responses regarding their care plan and needs related to cognitive, behavioural, and social supports in greater depth and without potential bias imposed by the wording of interview questions. Interviews were conducted by the first author, a researcher-clinician with over ten

years of experience providing clinical services to the pTBI population. All participants were known to the interviewer via the rehabilitation process. Interviews were audio recorded and later transcribed. To ensure inter- and intra-rater reliability of transcription, sampling transcription checks (20% of interviews) via re-transcription were completed.

2.3. Thematic analysis

After transcription, two second-year graduate students in speech-language pathology independently reviewed transcripts and grouped comments into categories based on initial perceptions of similarity using thematic content analysis. Closely linked to grounded theory, thematic content analysis is a qualitative data analysis approach that provides a framework for identifying, analyzing, and reporting patterns within a dataset [46,47]. Reviewers identify patterns in the dataset, based on the importance or prevalence of the data, and combine them to create themes [46,48]. Thematic analysis is used to examine the perspectives of participants, specify their similarities and differences, and elicit unanticipated information from the participants [47]. In the current study, thematic content analysis was conducted using the six-phase approach outlined by Braun and Clarke [46] (Figs 1 and 2).

The last author, a female Ph. D. researcher-clinician with a twenty-year history of working with the TBI population, then labeled initial categories into preliminary themes. Each of the graduate students then re-analysed utterances from each transcript to fit them into these five themes, along with a category for miscellaneous statements. Then, the two lead researchers (first and last authors) created a seventh theme that was not identified in the preliminary reviews. The lead researchers independently reviewed, then conferenced to compare the transcripts utterance-by-utterance, reaching 100% consensus on how utterances were labeled.

3. Results

Following the analysis of all interview transcripts, the following themes were identified for both care-

Table 3
Prompts for semi-structured interviews, by stakeholder group

Survivors of pTBI (varied depending on age of survivor)	Caregivers	Medical professionals
Tell me about what happened when you hit your head.	Tell me about your child's injuries.	Tell me about your experience working with children with brain injuries and their families.
What things are easy for you now? What things do you need more help with?	Tell me about your experience with the health care system as it relates to your child's injuries.	Tell me about your process of clinical decision making when providing treatment for this group.
Tell me about school, friends, activities outside of school.	Tell me about how prepared you felt to deal with your child's injury. What areas did you feel the most prepared? Least prepared?	Tell me about what you find works well in the treatment of children with brain injury.
Tell me about any special help you receive at school or home.	Tell me about how you were provided education about your child's injury.	Tell me what struggles you perceive in working with this population.
Tell me about how you felt during your recovery process.	Tell me about your experience returning to home. And school?	Talk to me about the monitoring of families and survivors after discharge.
Tell me what you learned about your injury. Is there anything you wish you had learned?	What advice would you give to other families in a similar situation? Or to your child's medical team?	What do you wish survivors and families knew about brain injury?

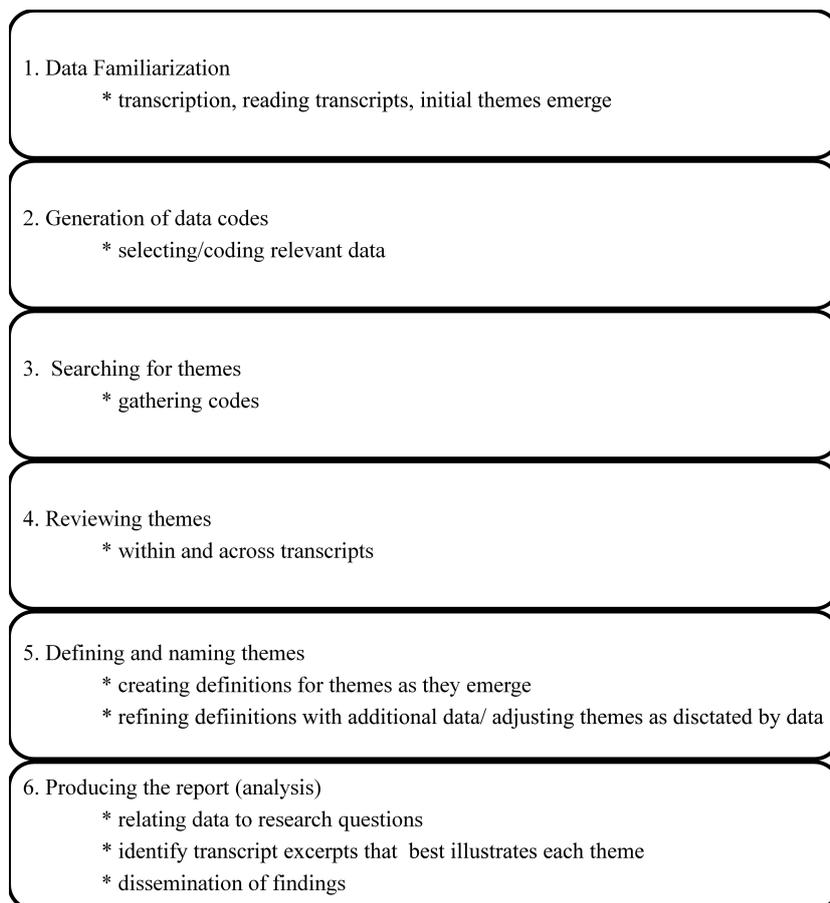


Fig. 1. Thematic content analysis.

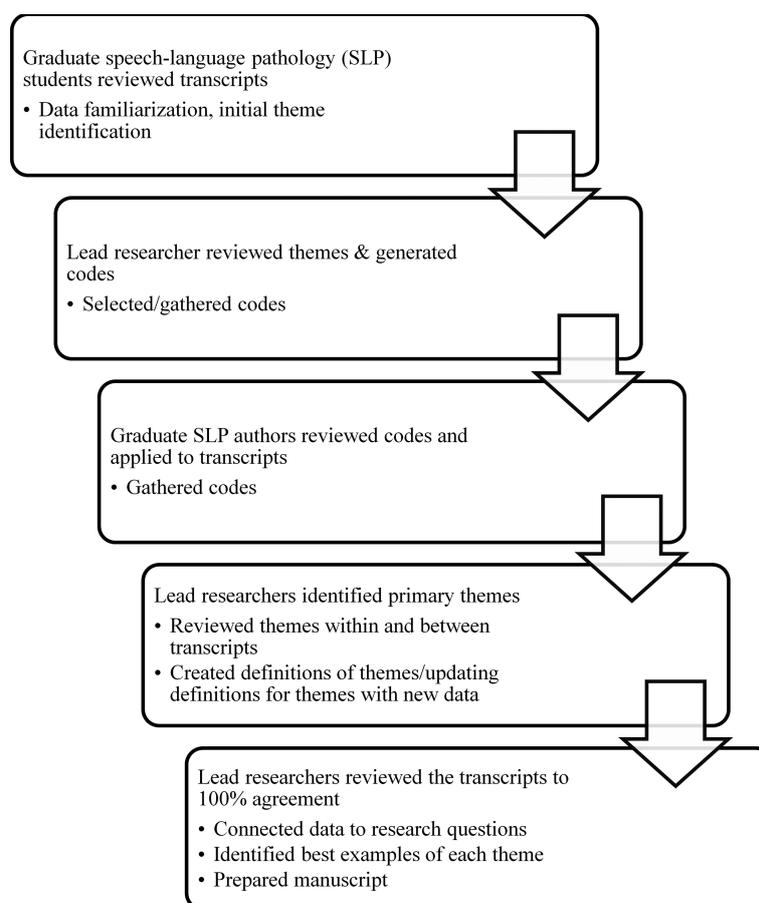


Fig. 2. Transcription procedure and reliability.

givers and survivors: experiences with medical personnel, later developing issues, hope versus reality, next steps, social issues, discharge, and miscellaneous. The following themes were identified for medical professionals: population characteristics, evidence-based patient centered care, staffing/teamwork, follow-up, and miscellaneous. Figure 3 shows the coding tree for these themes.

3.1. Caregivers and survivors

3.1.1. Experiences with medical personnel

[References to caregiver and survivor quotes refer to Tables 4 and 5 respectively. See also Figs 4 and 5.] Caregivers most frequently discussed their experiences with medical personnel, accounting for 18.1% of total comments (range = 13.3–22.1%). Overall, interactions were discussed positively when professionals were perceived to be working towards a specific caregiver goal (C1) or when they provided informa-

tion or updates to a caregiver often and with empathy (C2). Interactions that were described negatively included those in which communication among hospital staff was viewed as inconsistent (C3) or medical professionals were not responsive to the requests, needs, or insights of the caregiver (C4 and C5).

Survivors discussed their experiences with medical personnel less frequently. Survivors often commented that they did not remember the early part of their hospital stay, but did comment on interactions with the rehabilitation staff with primarily positive regard. This was the fifth most common theme expressed in survivor interviews, accounting for 7.4% of all comments (range = 0–17.9%).

3.2. Later developing issues

For caregivers, the second most frequently discussed theme related to issues that developed well after discharge from inpatient rehabilitation. This theme ac-

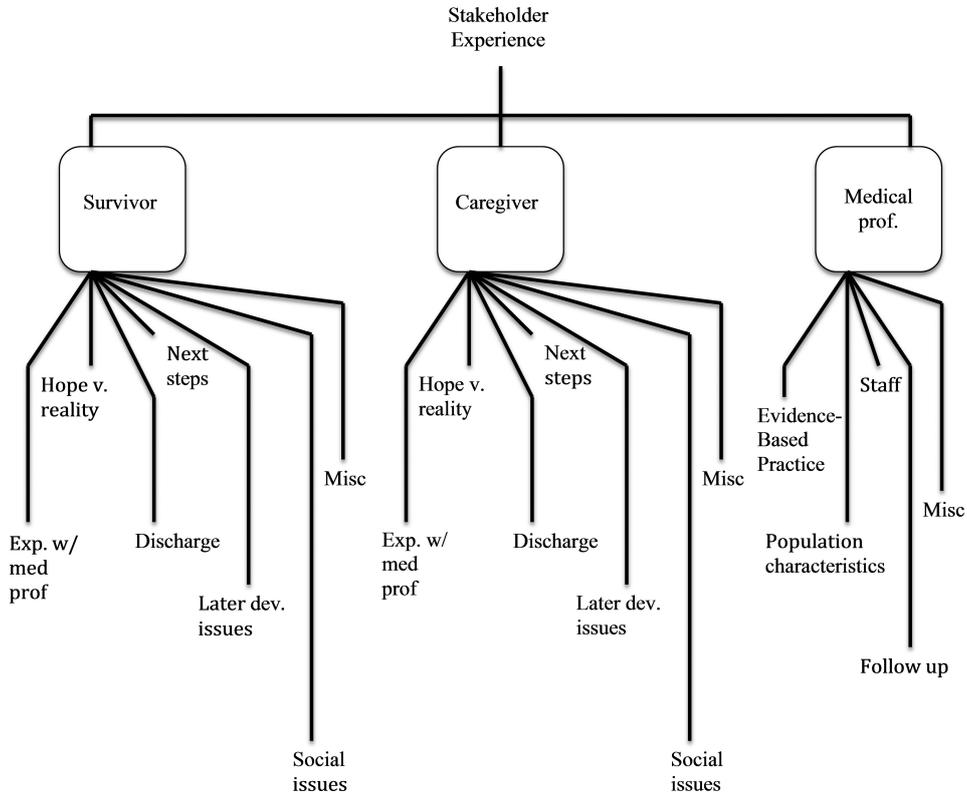


Fig. 3. Coding tree for interviews.

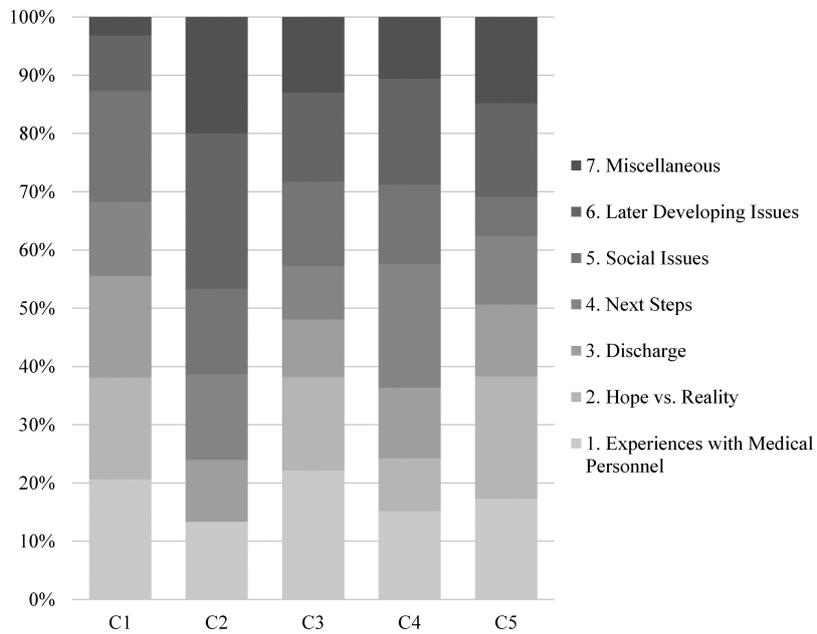


Fig. 4. Caregiver comments by theme.

Table 4
Examples of caregiver quotes for each identified theme

Theme	Caregiver quotes
Experiences with medical personnel	<p>Positive:</p> <p>C1: I put more faith in the nurses because they were absolutely phenomenal at X [hospital name]. They helped us get out the g-tube [gastrointestinal tube] and the trach [tracheotomy]. . . They said stuff we wanted to hear maybe. They were more personable. Or maybe because we were with them more.</p> <p>C2: I remembered a few people in the ICU [Intensive Care Unit]. I told them I wanted to be woken up, They would always explain what was going on. I always felt like I was up to speed. And the nurses, I could ask questions, and I felt good.</p> <p>Negative:</p> <p>C3: There was a point where we felt like maybe not all the doctors were talking to each other so we were very concerned about a doctor coming in and not knowing what the previous doctor had just told us.</p> <p>C4: Neurology would be one that was not as receptive to our thought process. Even post discharge visits, we had changed neurologist], things that had gone on in the office and anyway I feel like we still had the same treatment when you are greeted with "I'm not sure why you're here."</p> <p>C5: I don't think [palliative care discussions] should be presented . . . in a room where you are by yourself. I was by myself at that time and I think you should have a support system. So I think that would help to make sure that those conversations happen with a group of people that are around you to help you make a rational decision as well.</p>
Later developing issues	<p>C2: He's [S2] in this reading class – it's small, 10 kids, and the kids are not special needs, just slower – they just need additional assistance with comprehension and reading. I think his memory is so good for experiences. He really remembers experiences. He could tell you about a baseball game or a basketball game that happened a year ago.</p> <p>C1: He gets more agitated more quickly, and he doesn't realize it. He says it's because his family can take it and it's only with family. But he can be mean. And we tell him, even his little siblings see it.</p> <p>C5: You gotta fend for yourself once you get to the point of 'hey he's getting much better.' And I am excited for him to do that don't get me wrong, but he still needs support, and you can't just pull the support away like a rug out from beneath your feet. I feel like that kind-of happened to us.</p> <p>C3: And of course the biggest, number one issue is, what's going to happen to her when we die? That's the one that's out there and is the biggest and most important is who's going to take care of her and watch out for her?</p>
Hope versus reality	<p>C1[a]: The main neurosurgeon was not in the room to talk to us, the resident was there and told us "There's no hope. He's got widespread DAI [diffuse axonal injury], severe TBI, and we don't see much hope." And it was like OK and I lost it and left the room and threw-up.</p> <p>C1[b]: I didn't believe that he [S1] wouldn't know who I was. I thought he was going to be fine. In my mom-head. But he was not in there, so to say. For a mom, this is so temporary, things will come back. I was very optimistic. I put myself in a hope bubble, and there was no way my kid was not going to recover fully. There was no way he was not going to make it or be in a vegetative state.</p> <p>C4: . . . So things that they'd relay to us and things we have shared with [S4], so this isn't his first time hearing - it was a lot of "He will never's." It's not likely he will walk again. It's not likely he will function in normal society. He may never eat on his own again. He may never do a lot of these things. You know it just kind of, we were taken aback by that, and that's kind of when my husband and I made a pact and said, "Ok this is not us and this is not what we want for our son."</p> <p>C3: So many parents shut down the minute they hear something negative that it doesn't really matter what you say after that, they are not gonna hear it. If its too negative it's also like "Well I'm not gonna believe that." You get stuck on that one thing they said and you miss the rest of what was told. I think keeping it as positive as possible. I know you gotta keep the reality in there too, but starting with the positive and letting the parent say what their expectations are first. Then you can guide everything towards that expectation while still being realistic. Parents would stay engaged a lot longer and be able to hear what you're saying longer.</p> <p>C5: At points you know people would say, "Well you're gonna have to get used to a different person" and that ended up not being true for us. But I guess things that I would want to change would be kind of bedside manner as far as what to expect. It was kind of black and white, which I understand they have to be, but there is a gray area. And I think you should always have hope.</p>
Next steps	<p>C1: You need to find out how people are doing every 6-months. . . . Therapists and doctors start going away. It's like weaning.</p> <p>C3: The hospital system is great but once you leave you have to get connected with the other systems like Medicaid, family services, school system etc. It would be great if there was a case manager that could really follow through all the way around.</p> <p>C4: I feel like as the child grows into an adult, you lose that connection. He was only 17 when we came back so when we notice changes I want to be able to have some kind of resource to tap into. And what to expect? Do we need to come annually? Is it every 2 years, every 5? Is it "Oh hey you never have to come again?" That is the piece I feel like we are just left hanging with out there.</p>

Table 4, continued

Theme	Caregiver quotes
Social issues	<p>C2: Well, S2 keeps talking about football, and he says “I can’t play because I can’t catch the ball.” Well, this friend has asked him to play football at recess, and so [S2] is going to try to play at recess, and he tells his friend, “I’m going to try my best to catch the ball,” and this friend says, “I’ll make you my running back.” And they let him play quarterback sometimes, and one time [S2] caught the ball. He [S2] came home and he was so excited. ... I’m very thankful that there are some good kids and good families out there.</p> <p>C1: I tried to sit down with teenagers and I tried to explain why he’s [S1] doing these things. ... Some of the older grades were nicer and more understanding, and they got it better, but everyone younger (shakes head no).</p> <p>C3: At some point [S3’s dad] connected with another dad in the hospital. It just so happened there was another girl in the hospital with a similar injury and he connected with him [the other dad]. That dad also said “I don’t have anyone to talk to.” So they connected through email because she left soon after that.</p> <p>C4: I think it would be nice to see a newsletter come out and say “Hey here’s this new support group if you are interested in participating, get together at this time.”</p>
Discharge	<p>C3: I remember the day that they told us we were going home was total panic. Oh my gosh we are so not ready for this. [The staff] were trying to show us how to [draw up medication in a syringe] right before we left and we were like, “We are already panicking about trying to take her home in the first place, staying up around the clock.”</p> <p>C5: As far as resources go, you’d watch videos on the rehab floor, of different things. ... You gotta watch out for seizures, other things that you had to be trained on. That’s very important. But it doesn’t really show what someone goes through as far as the brain injury. When you get home, it doesn’t show that aspect. It just shows “okay this is what you do in case of this” but it doesn’t show you. ... “Man when I walk out there and this is real life again. ...” Wow. You need to be prepared for hard work. You need to be prepared to not sleep. You need to be prepared be the nurse, the doctor, the teacher, the therapist, be it all.</p> <p>C2: ... I had practice at the hospital. For a week or 2 before he left, I got to take him out for a day at a time. ... It was good to practice.</p>
Miscellaneous	<p>C1: You realize the care in the US is a helluva lot better than in other places, but they might be able to get better drugs – or use the hyperbaric chamber, whereas here that is experimental and so expensive.</p> <p>C5: So we were hit in an automobile accident and [S5] was a front seat passenger restrained. He sustained an axonal diffuse brain injury, left forearm fractures, dislocation in his forearm, bilateral tib- fib fractures. ...</p>

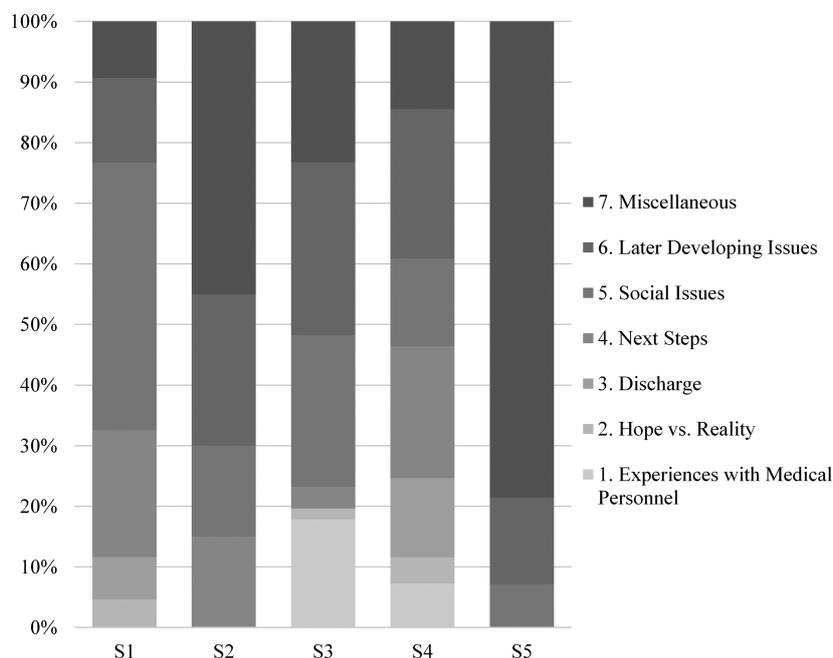


Fig. 5. Survivor comments by theme.

counted for 16.9% of total caregiver comments (range = 9.5–26.7%). Caregivers reported both positive and negative observations that occurred after initial injury

and recovery period (C2), ongoing needs or more recently developing concerns (C1 and C5), and contemplating the future for their child (C3).

Table 5
Examples of survivor quotes for each identified theme

Theme	Survivor quotes
Experiences with medical personnel	S3: I only remember being outpatient. I remember it was good because I was really able to form close relationships with each of my therapists whether it was OT, PT, or speech. S4: [Therapists] or [step-dad] was always with me when I was doing therapy or working on stuff.
Later developing issues	S1: Before the accident I was really gifted in [math]. I was going into engineering, and after my injury it was really hard, so I had to change my major. S1: When I'm tired, when I'm talking to my speech therapist, when I'm excited to say something or have a lot to say, sometimes I get – like all my thoughts are trying to get out the door and I kinda jump the gun, and say too much, all these words trying to get thru the door, too many at once, and it doesn't happen. S4: So in order to focus on more than one thing, I used to be able to do that great, but now it's like I have got to write it down or put it in my phone or something because it won't happen if I don't.
Hope versus reality	S4: Like [C4] said. It took a while for me to really realize that I would never do the stuff I used to do, you know at the level I used to do it at. S4: Even though they told me and my parents told me, you never want to believe it because you fall back to what you used to do like "I was good at this" but now you're not.
Next steps	S1: I got extra time, an aide – she helped with navigating the school, getting class to class, if I needed or wanted something. She would say "better write that down" or whatever. S4: I think anger was the worst [unexpected challenge]. I always get mad at [my step-dad] when we do therapy. For one, you are with them every day doing it. You know you work hard and when [they] push, you tend to get a little aggravated if you don't see the progress you see [on rehab]. It's all getting put on the line and the one that's pushing you now is your parent. Anger was the worst part. I know I snapped at him a few times. I felt terrible, but it just came along with what was going on.
Social issues	S2: [making friends] Its easy. I have a best friend. I made friends. I know some kids, not in my grade, who know a lot of people. S1: Once I got out of the hospital, they tried. They would invite me out a bit, and I was so different obviously, and [they] stopped answering my texts, wouldn't pick up. I would be face-to-face, and they wouldn't even respond. But, I didn't have a lot of awareness, so I wouldn't understand it; they would talk down to me. Now I realize they were putting me down. S3: Dating is nonexistent right now but I am hoping to. But friends, you know my friends have moved on with their lives. S4: Your good friends will stay but the ones that are there because of what you're doing at the time. Most of those guys were just there for the ride because of what was going on. The good friends stayed and we still talk a lot, so I didn't really lose anything that was worth keeping. It was a big deal to me at first but now it's cool.
Discharge	S1: This [situation] might be hard, but we'll put you in a situation and we'll test it and help you deal with it, like a real-world situation. You have to be put in a real situation [to be prepared to go home]. S4: So whenever I did get discharged from [inpatient rehab], I could carry on with what we kind of built [on rehab].
Miscellaneous	S1: I graduated [from high school] on time because I was so far ahead. If I wasn't so far along, it might've been harder. I only needed 1.5 courses. S2: I have two things I wanna be, a construction worker and get all dirty and make stuff, or in an office, like [names a local company]. S5: We do the pledge of allegiance and the calendar. And then we check our schedules. Every morning when we are done eating we brush our teeth and then we do yoga. Then the speech. . . Then we get ready to leave. Then we wait for the bus. . .

For survivors, later developing issues experienced after pTBI were the third most commonly discussed theme, accounting for 22.8% of total survivor comments (range = 14.0–28.6%). Survivors discussed life changes that occurred after the injury and challenges that are noticed many years post-injury.

3.3. Hope versus reality

The third most common theme discussed by caregivers related to the competing experiences of hope and reality. Caregivers commented frequently on the impact of receiving difficult news from the medical staff (C1[a]) and the need to continue to hope for the

best possible outcome for their child despite indications to the contrary (C1[b] and C4). Caregivers also spoke about how medical professionals could provide hope while also remaining realistic (C3 and C5). This theme accounted for 14.5% of total caregiver comments (range = 0–21.0%).

For survivors, on the other hand, hope versus reality was the theme discussed with lowest frequency. Comments addressing this theme accounted for only 3.0% of total survivor comments (range = 0–4.7%).

3.3.1. Next steps

Caregivers discussed issues related to transitioning from inpatient rehabilitation to home and school in

Table 6
Examples of medical professional quotes for each identified theme

Theme	Medical professional quotes
Evidence-based practice	RN: I don't feel like there's as much evidence on BI – on SCI, there's a ton. Especially for nursing. TR: As far as TR in general, there is not really a ton of solid research in general to support our treatment so I think that's definitely something that is needed and hopefully something we can work toward in the future. SLP: But I think there's not a lot of research to support a lot of the interventions or assessments that we're doing. Even not just in speech pathology, but in pediatrics in general.
Population characteristics	RN: One of the most challenging things is watching the families grieve... but it's fun to see the progress they make so quickly. TR: Working with patients with BI can be really challenging and really rewarding. When they come to rehab they're in very acute stage of recovery, it is really neat to see their progress, we see patients coming and doing almost nothing, not talking/able to move, and not able to walk, and we see them go home, they're walking, talking and functioning close back to where they are before. SLP: With the BI population you don't always know exactly what the outcome will be, but we can follow that progression and sometimes you have an inkling that, you know, it's Friday, I have a feeling that Monday they're going to be talking. And you come back and they're a totally different person. That is the most rewarding.
Follow-up	RN: From a nursing standpoint, I would love to see us getting more feedback on when they go home, what's with the safety issues with friends, the difference they appear to have with their friends, do they get into drugs? We educate them, before they leave, what all their risks are for their choices and being more impulsive with things. They are more at-risk for drug and alcohol usage. I'd like to hear if that stuff did/didn't happen. I'd also like to see school-wise how they ended up. TR: Like long-term how they do, even into adulthood. I think it's always interesting to see, you give them all this information and educate them on activity restrictions, and maybe new activities they can try or do when they go home, and to hear what they've actually done when they go home. SLP: Could we do something else to follow-up? Sometimes we have to do a phone call? Could we do a skype call? Is there some other way we could do follow-up? So, then after 2-months, they fall off the face of the planet?
Staffing/teamwork	RN: I feel like our biggest thing is communicating with them properly, and getting information on how they're doing. TR: It's helpful to have a panel meeting once a week where we all communicate, and talk about a patient, and what their needs are, there always needs to be communication somewhere. This can happen whether it be through orders, or one-on-one communication to the nurse, or notes. SLP: I feel like we, as therapy staff, do a good job communicating with each other, but the break-down tends to be with nursing and PCA [patient care assistant] staff. We've tried a lot of different things, and recently we've had a lot of turnover with nursing and PCA staff and that has made things a challenge.
Miscellaneous	SLP: I don't know the show rate [for outpatient clinic]. It's not great. I think we have a lot of families that don't come.

12.9% of total comments (range = 9.2–21.2%). In addition, caregivers discussed their perceptions of the care continuum for persons with TBI. Comments frequently related to their feelings of disorientation, in particular, the challenges they faced in coordinating care for their child once they were no longer supported by the inpatient rehabilitation team.

Survivors discussed these issues in 14.4% of total comments, making it the fourth most commonly discussed topic (range = 0–21.7%). Survivors spoke about outpatient therapies, supports they received upon return to school, and unexpected challenges that arose at home (S4).

3.4. Social issues

Social challenges related to pTBI were raised in 12.5% of caregiver comments, making this theme the sixth most commonly discussed issue (range = 6.8–19.1%). Caregivers reported a variety of social issues, both positive (C2) and negative (C1), for their child,

and also discussed the importance of social support for themselves (C3, C4).

Survivors, on the other hand, discussed social issues related to pTBI most frequently. Nearly one quarter of all survivor comments related to this theme (23.3%; range = 7.0–44.2%). Younger survivors of pTBI had a more positive perspective on social issues, specifically friendship (S2), whereas older survivors reported the loss of friends after the injury and difficulty with finding or maintaining friends in the longer-term (S1, S3, S4).

3.5. Discharge

Issues and topics related to discharge from inpatient rehabilitation were the least common topic discussed during caregiver interviews. Discharge-related comments accounted for 12.1% of all caregiver comments (range = 10.0–17.5%). Caregivers often discussed a sense of anxiety and feeling ill-prepared for discharge (C3 and C5), as well as methods to improve confidence prior to discharge (C2).

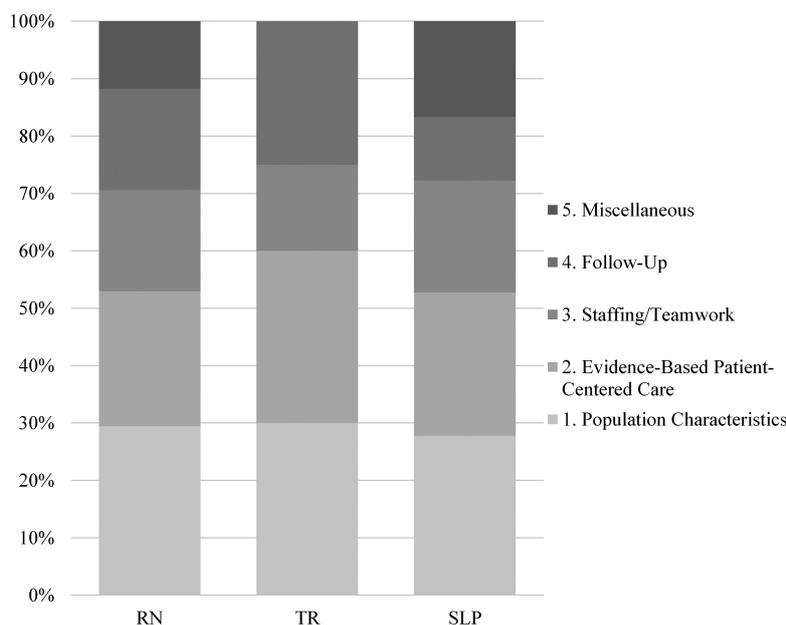


Fig. 6. Medical professional comments by theme.

Only two survivors made discharge-related comments that focused on the therapy staff preparing the survivor to go home. This was the second-to-least frequent theme mentioned by survivors and accounted for only 5.9% of their total comments (range = 0–13.0%).

3.6. Miscellaneous

Caregivers and survivors provided a range of comments that did not occur frequently enough to create distinct categories. Caregiver comments were designated as miscellaneous in 13.1% of cases, making it the fourth most commonly occurring theme (range = 3.2–20.0%). These comments often included other thoughts about care (C1) and injury stories (C5).

For survivors, miscellaneous comments were the second most commonly occurring theme, at 23.3% of total comments (range = 9.3–78.6%). These comments included topics ranging from pre-morbid issues (S1), current activities (S5), and plans for the future (S2).

3.7. Medical professionals

3.7.1. Population characteristics

[See Table 6 and Fig. 6.] For medical professionals, the theme most commonly occurring during interviews related to the challenges and rewards of working with survivors of pTBI and their families. Providers uni-

formly discussed the energy that they derive through witnessing the progress made by many pTBI survivors during their relatively short hospital and rehabilitation stay. This theme accounted for 28.8% of total comments (range = 27.8–30.0%) and was discussed with similar frequency across disciplines.

3.7.2. Evidence-based patient centered care

Across disciplines, the perceived lack of evidence-based approaches for assessment and treatment of pTBI was highlighted, making it the second most discussed theme for medical professionals. These comments accounted for 26.0% of all interview comments. By profession, these comments accounted for the following frequencies: Registered Nurse (RN) = 23.5%, Speech-Language Pathologist (SLP) = 25.0%, and Therapeutic Recreation Specialist (TR) = 30.0%.

3.7.3. Staffing/Teamwork

During interviews with medical professionals, 17.8% of total comments related to staffing and issues surrounding the interdisciplinary rehabilitation team (range = 15.0–19.4%). This theme was the third most frequently discussed amongst the medical professional group. The medical professionals discussed the importance of team communication (RN), the areas of weakness in team communication (TR), and ways that team communication can be supported (SLP).

3.7.4. Follow-up

The providers uniformly commented on the desire

to understand what happened with survivors and identified the need for creative approaches to be able to follow survivors after discharge. Follow-up was discussed in 16.4% of total interview comments (range = 11.1–25.0%). During the TR's interview, this theme accounted for 25% of all comments.

3.8. Miscellaneous

There were few miscellaneous comments within the medical professional group, which often related to the professionals' description of their work experience. For medical professionals, comments were determined to not fit the established themes in 11.0% of cases (range = 0–16.7%).

4. Discussion and clinical implications

When a child experiences a TBI, there is significant stress within the family unit [49]. Past research has identified several familial psychosocial factors that can impact the overall outcomes for survivors of pTBI, including family stress [50,51], access to resources [50, 52], and parental coping style [51,53]. By extension, if psychosocial risk influences outcome, it would be reasonable to consider that the actual lived experience of the caregiver and survivor of pTBI might influence the ultimate outcome of the survivor. For example, a person's feelings about their medical experience or the information received about pTBI might impact the likelihood of seeking services once the child returns to school. Yet, there is little discussion in the literature about the survivor and family experience following pTBI and how these experiences might relate to unmet needs [34,36,37]. In the current study, nearly 50% of caregiver comments fit into the first three themes: experiences with medical professionals, later developing issues, and hope versus reality. These findings are consistent with past reports suggesting that families require significant support not just during the acute stages of recovery following pTBI, but during the chronic stage as well [2,18,19,54].

Discussions about later-developing issues were prominent for both caregivers and survivors. Caregivers specifically discussed how these issues created challenges, often related to not knowing when, where, or how to seek help to address identified needs. The frequency of these comments by both groups of stakeholders is consistent with past research discussing unmet needs following pTBI [10,17–19,23]. Survivor

comments from these interviews also emphasize the importance of the social implications of pTBI on the survivor, especially during adolescence. Since there are few evidence-based interventions to assist teens in this realm, the frequency of these comments highlights how research and clinical practice are not addressing a need that is important to the stakeholders. As the lived experience of key stakeholders matches the growing body of literature demonstrating that children with pTBI may demonstrate delayed consequences of the injury on later developing skills, the medical and educational communities must respond with improved care pathways that improve both access to and receipt of services for children with pTBI and their families.

Consistent with gaps in care identified in the 2018 Report to Congress on the Management of TBI in Children [19], caregivers and medical professionals interviewed for this study stressed that consistent care providers and those with specific knowledge of pTBI are optimal to assist families and survivors of pTBI during all stages of recovery. The complex issues associated with long-term recovery following pTBI indicate how implementation of a medical home concept might improve the long-term care following pTBI. Previous literature examining other pediatric chronic conditions [54,55] suggests that a consistent medical care team that includes supports for the family decreases unmet needs and facilitates transitions into adulthood. Since unmet needs are a particular challenge following pTBI, improvements to the continuum of care following pTBI would be a direct response to the stated needs of key stakeholders but also help to ameliorate existing problems related to service provision and access.

Additionally, the inclusion of stakeholder perspectives could be a critical and missing ingredient to identifying best-possible evidence-based practice approaches in pTBI. Medical professionals from different disciplines interviewed for this study all identified the lack of evidence as a particular challenge to providing good care to children with pTBI. These comments are supported by studies that demonstrate variability in the services available to children and the quality of those services [56]. Also, despite having only three disciplines represented in this pilot study, these comments echo findings from a recent Canadian study where 15 individuals from six healthcare professions expressed similar thoughts in focus group meetings [57]. The perspectives of key stakeholders should help researchers and clinicians identify the most salient and impactful directions for future work.

4.1. Limitations and future directions

While designed as a pilot study, the generalization of the findings presented here is limited by small sample size. Enlarging the sample would allow for greater characterization of comments that were included as miscellaneous in this study and allow for minor theme identification per COREG suggestions [43]. In a larger study, it will be critical to include persons from minority groups to allow for greater diversity of perspectives. It is likely that persons from non-white groups might report different experiences and perceptions of care following pTBI, as disparities in care and disability have been found in non-white patient groups [58]. Future research should also include representation from other disciplines involved in caring for children with pTBI. Additionally, since research shows that children admitted to inpatient rehabilitation are more likely to have hospital-to-school transition planning and establishment of outpatient therapies [59], we must expand this work to include those patients who do not receive acute rehabilitation. This is especially critical because it is estimated that only 4% of children who sustain a pTBI are admitted to an inpatient rehabilitation unit [60]. Lastly, as we move forward and increase sample size, we will incorporate the iterative process of allowing participants to review their transcripts and provide feedback on the findings.

4.2. Conclusions

The consideration of the perspectives of key stakeholders affected by pTBI gives depth to the trends that are present in the literature and provides insights into how our current system of care can be improved for all stakeholders. Specifically, caregivers and survivors are in need of an improved continuum of care that supports later developing challenges that arise long after hospital discharge. Additionally, survivors require greater support in managing the social challenges they may face following a TBI, and medical professionals are in need of a stronger evidence-base to support their clinical practice. Despite the wide variations in age and injury severity of the participants included in this pilot study, there are commonalities that appear when taking into consideration stakeholder perspectives related to pTBI. These perspectives should be central to driving innovation in rehabilitation research and clinical care.

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Conflict of interest

The authors have no conflict of interest to report and there is no funding associated with this work.

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