ASSISTING CHILDREN’S MEMORIES OF THEIR EARLY ACUTE CARE HOSPITAL EXPERIENCES FOLLOWING TRAUMATIC BRAIN INJURY

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Abstract

**Purpose:** The aim of this study is to highlight the importance of collecting patient care diaries, pictures, and other narrative accounts to fill in children’s memory gaps from their early acute care period following severe TBI and to determine factors that influence children’s perceptions of these interventions.

**Background:** Many times, children with TBI are admitted to the ICU following their injury. Although early acute care is aimed at stabilizing the patient’s physical condition, many children are left with long-term negative psychological outcomes due to their gaps in memory from this time. Therefore, interventions have been developed to help prevent long-term negative psychological outcomes.

**Methods:** A secondary analysis was employed using interview transcripts from a previous study focusing on children’s experiences following moderate to severe TBI. Transcripts from children with severe TBI were evaluated to see how they viewed such interventions. Three participants from the original study were selected as exemplars of the three types of responses received (positive, negative, or mixed), and their interview transcripts were analyzed to determine how they perceived the utility of interventions used to fill in their memory gaps.

**Findings:** Each of the three subjects from the original study had varying perceptions on the benefits of the interventions used to fill in their memory gaps. While 13 of the children from the original study were not exposed to such interventions, participants who were exposed found that the use of pictures with written or narrative accounts of their early acute care period had positive perceptions of filling in their memory gaps.
**Conclusions:** Participants viewed the use of pictures in addition to other written and verbal accounts as a helpful way of connecting their past to their present. Therefore, it is important to consider pictures and other narrative accounts to improve children’s long-term psychological outcomes following severe TBI. However, it is important to be careful to allow the child to choose whether they would find these interventions helpful.
Introduction

Traumatic brain injury (TBI) and its long-term effects among pediatric populations is a very important topic considering TBI is the leading cause of disability among children in the United States and comprises almost 37,000 pediatric hospitalizations per year (Jimenez et al., 2013; Walker et al., 2009). Some of the long-term effects of TBI in the pediatric populations include deficits in cognition, language, memory, and psychosocial functioning (Nadebaum, Anderson, & Catroppa, 2007). Typically, the severity of a TBI is classified by using the Glasgow Coma Scale (GCS), with mild TBI defined as a GCS score of 13-15, moderate TBI as a score of 9-12, and severe TBI as a score of 3-8 (Nadebaum et al., 2007). Children and young adults with moderate to severe TBI are typically hospitalized in an intensive care unit (ICU). Admission to an ICU is usually associated with positive physical outcomes due to advances in medical technology and specialized critical care practices. However, negative long-term psychological effects are now being associated with stays in an intensive care unit (Ewens, Hendricks, & Sundin, 2014; Rennick & Rashotte, 2009; Egerod & Bagger, 2010; Colville, Kerry, & Pierce, 2008; Dow, Kenardy, Long, & le Brocque, 2012).

One area that Colville, Kerry, and Pierce (2008) focused on when evaluating negative psychological sequelae following discharge from the PICU was factual and delusional memories children can retain from their hospitalization. However, there was a secondary finding in the study that revealed children discharged from the PICU secondary to TBI were 77% more likely to have no recollection of their early acute care period (Colville et al., 2008). There are many factors that influence this loss of memory, including trauma from the injury, coma, and pharmacologic interventions (Lee et al., 2013; Colville et al., 2008). This gap in memory can be distressing to children following TBI and affect their long-term sense of self once they return
home and attempt to reintegrate back into their social routines (Roscigno, Swanson, Vavilala, & Solchany, 2011). However, there is minimal research surrounding the rationale or process of orienting children to their early acute care period (the time from admission to the ICU to discharge from rehabilitation). Subsequently, little is known about how children may react emotionally to interventions used by family, friends, or healthcare providers to fill in their memory gaps.

Background

Many times children who suffer a severe TBI enter a comatose state. Comas following a severe TBI can last anywhere from days to months (Lee et al., 2013). A coma is defined as a continuous loss of wakefulness and awareness for six or more hours, along with the inability to respond to external stimuli or produce voluntary movement (Lee et al., 2013). Comas secondary to TBI are directly related to trauma (Stevens, Hannawi, & Puybasset, 2014). Injury to the brainstem and diencephalon are responsible for losing consciousness, while injury to the cortical areas of the brain are responsible for deficits in cognition (Stevens et al., 2014). Comas play a significant role in memory loss following moderate to severe TBI.

With comas, it is important to monitor both the progression of the coma and signs of emergence from the coma. However, monitoring emergence can be quite difficult (Nenadovic, Velazquez, & Hutchison, 2014). Electroencephalography (EEG) can help identify when patients are emerging from comas, but the validity and reliability of this is questionable with TBI (Nenadovic et al., 2014). Other highly specialized and expensive technology such as PET scans can be used to monitor coma emergence, but the expense and availability of PET scans limits its use (Lee et al., 2013). Therefore behavioral assessment tools such as the JFK Coma Recovery
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Scale-Revised, expanded GCS scale, and Ranchos Los Amigos Levels of Cognitive Functioning scales are used to monitor the prognosis and progression of comas (Lee et al., 2013).

Although highlighting aspects of the coma process is important when considering memory gaps following TBI, it is also crucial to highlight other aspects of the early acute care period. Many times severe TBI requires specialized care in an ICU. While the main goal of ICU care is to stabilize the patient’s physical condition, many of the treatments can be traumatic or invasive (Rennick and Rashotte, 2009). One study found that the average child undergoes 88.73 invasive and non-invasive procedures in the ICU, which was 394% more than children in the same study who were not in critical care units (Rennick & Rashotte, 2009). Children in the ICU are also subject to an onslaught of psychological stressors, such as dealing with their fragile physical state and life-threatening condition (Dow et al., 2012). Often times, children in the ICU are sedated with benzodiazepines, and their pain is treated with opioids (Dow et al., 2012). Studies have shown there to be a strong link between medical sedation and negative psychological outcomes (Dow et al., 2012). Negative psychological sequelae following hospitalization in an ICU is now a recognized phenomenon and has become the subject of nursing and medical research alike (Dow et al., 2012; Rennick & Rashotte, 2009).

The causes of negative psychological sequelae following severe TBI are multifactorial (Ewens, Chapman, Tulloch, & Hendricks, 2014). Studies in adults reveal that the patient’s personal appraisal and memory of their hospitalization play a significant role in whether the patient develops negative psychological sequelae (Dow et al., 2012). Also, benzodiazepines and opioids that adults receive in the hospital increase their risk for developing psychopathology (Dow et al., 2012). However, the correlation between benzodiazepine and opioid use and negative psychological outcomes has not been substantiated in pediatrics. Nevertheless,
admission to an ICU is associated with negative psychological outcomes in pediatrics (Dow et al., 2012).

Isolating particular factors that lead to negative psychological outcomes in children is difficult due to the children’s developing cognitive function (Dow et al., 2012). However, pre-admission psychopathology, limited family visitation, and the child’s appraisal and memory of their hospitalization are factors that affect the patient’s susceptibility to negative psychological outcomes (Dow et al., 2012). Therefore, research is now focusing on interventions to prevent negative psychological outcomes following admission to an ICU (Turner et al., 2012).

One of the most widely used interventions to prevent negative psychological outcomes following ICU admissions is patient care diaries (Turner et al., 2013; Ewens et al., 2014; Egerod and Bagger, 2010). Typically, patient care diaries include writings from family members, friends, and healthcare staff that document the events of the patient’s hospitalization (Egerod & Bagger, 2010; Turner et al., 2013). Often times, photographs of the patient are included to help assist patients in addressing their gaps in memory (Ewens et al., 2014). It has been postulated that the helpfulness of patient care diaries stem from their ability to help patients see their injury differently (Ewens et al., 2014). Care diaries also give the patient physical evidence of the care given to them by both the healthcare staff and their family (Ewens et al., 2014). However, there are very few studies that focus on how children respond to reading diaries or seeing pictures of themselves from their early acute care period following TBI. Although adults tend to respond positively to patient care diaries, a study in Australia found that some adults experience distressing emotions after reading their diaries (Ewens et al., 2014). However, adults have the coping mechanisms to deal with the distressing emotions and use the diaries as a tool to come to terms with their injury (Ewens et al., 2014). However, very young children may lack the ability
to cope with negative emotions brought on by diaries or pictures. Therefore, it is important to understand how children respond to journals, pictures, and verbal accounts detailing their early acute care period.

**Methods**

**Purpose**

The purpose of this secondary analysis, using a case study approach, is to illustrate the utility of collecting patient care diaries, pictures, and other narrative accounts, should children wish to utilize this information to fill in their gaps in memory following severe TBI. This study also seeks to understand what factors influence how diaries, narrative stories, and pictures from a child’s early acute care period following severe TBI are interpreted. Transcript data from an originally study which employed descriptive phenomenology was used for this secondary analysis. Before analyzing any data, IRB approval was received. In order to ensure confidentiality, all patient information was de-identified for the secondary analysis, and pseudonyms were used as exemplars.

**Participants**

There were 39 children included in the original study, and these children were from 13 different states across America. However, it is important to note that the term *children* does not refer to the participant’s age. Rather, for this study, the term children refers to the participant’s relationship to their parents. This definition is important considering many of the participants were young adults by the end of data collection.

There were many different types of recruiting strategies utilized for the original study, including personal solicitation, nationwide advertisements through two TBI websites, posters in
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communities, newspapers, and mailing lists obtained from a brain and spinal cord injury program and pediatric trauma registry (Roscigno et al., 2011). Children were included in the original study if they: (a) were between 6-18 years of age at enrollment; (b) were diagnosed as having moderate to severe TBI (Glasgow Coma Scale of < 13); (c) possessed the capability to give assent/consent and the ability to engage in an interview; (d) were within 4 months to 3 years post-TBI at enrollment; (e) were still considered a dependent of either their parent(s) or other legal guardian(s); (f) were fluent in English; (g) obtained consent from their parent(s) or legal guardian(s) if they were a minor (Roscigno et al., 2011). Potential participants were excluded from the original study if they sustained a spinal cord injury along with their TBI or had a previous diagnosed developmental disability (Roscigno et al., 2011). Recruitment for the study was ongoing until the sample demonstrated reasonable diversity in the children’s developmental levels, genders, injury severities, family incomes, and living situations (Roscigno et al., 2011). The study also tried to recruit a diverse racial and ethnic sample through targeted attempts, but these aspects of the sample were not diverse (Roscigno et al., 2011).

Data Collection and Preparation

When potential participants expressed interest in the original study, in-person or phone meetings were set up to discuss the details of participating (Roscigno et al., 2011). Initial meetings were scheduled at a time when both the child and parent(s)/guardian(s) were available (Roscigno et al., 2011). All questions regarding the details of the study were answered before moving forward. The investigator also used this time to evaluate the children’s desire and ability to participate in an interview. At the end of phone meetings, verbal consent was obtained so that the researchers could make travel arrangements for an in-person interview (Roscigno et al.,
Children in the original study took part in two semi-structured interviews, each lasting 90 minutes or more (Roscigno et al., 2011). The content of the children’s interview was audio-recorded, transcribed, and checked for accuracy (Roscigno et al., 2011). The transcripts were the primary source of information for this secondary analysis. The first interviews were done in-person, typically at the participant’s home. The average time between the participant’s injury and the first interview was 15 months (a range of 4-36 months) (Roscigno et al., 2011). Precautions were taken to ensure privacy for the children’s interviews. Interview questions were semi-structured, open-ended, and focused on obtaining the children’s experiences and post-injury views of their daily life (Roscigno et al., 2011). Second interviews took place 12 to 15 months after the first interviews (Roscigno et al., 2011). The purpose of the second interview was two-fold: (a) to record the participant’s experiences since the first interview; (b) to evaluate the accuracy of and build upon themes developed in the first interview (Roscigno et al., 2011). For this secondary analysis, we only included children with severe TBI because they are more likely to experience memory gaps due to the diffuse nature of their primary and secondary injuries. Also, the participants with severe TBI expressed more difficulty with coming to terms with their experiences.

Several experiential themes were uncovered in the original study that described the difficulty children had in making sense of memory gaps from their early acute care period of recovery. (Roscigno et al., 2011). Probing questions were used to determine how the children felt about interventions used to fill in these memory gaps. The original study team found this topic to be very important to many children. The team also found the children’s perceptions surrounding
interventions used to fill in their memory gaps had a significant influence on their overall experience and meaning making following their injury.

**Data Analysis**

In this secondary analysis, a case study approach was employed to explore the various types of responses children had to interventions used to fill in their memory gaps (Stake, 1995; Yin, 1984). The children’s responses to the interventions were classified as positive, negative, mixed, or unable to be classified. In order to deeply explore the full spectrum of possible emotions children in this population might have experienced related to the research question, three specific participants were selected by the primary investigator to represent the positive, negative, and mixed perspectives. Their interviews were analyzed by T.C. and C.R. (primary investigator of the original study) in order to determine the factors that influenced how each child perceived pictures, written narratives (i.e. diaries, cards, emails, care page websites, etc.), or verbal accounts describing the child during their early acute care phase of recovery. The cases for this study were selected because the children had differing views surrounding the interventions used to fill in their memory gaps. (Stakes, 1995; Yin, 1984; Ayers, Kavanaugh, & Knafl, 2003).

**Results**

Out of the 25 children with severe TBI included in this secondary analysis, all participated in the first in-person interviews and 23 participated in the second interviews (92%). Children’s narratives about the use of written, pictorial, or verbal stories from others were classified as positive (n=5), negative (n=2), mixed (n= 3), or unable to be classified (n = 2).
These emotions were related to the child’s discussion of pictures, written narratives, or verbal stories about their early acute care period.

**Positive Experience**

Through careful analysis of Jason’s interviews, it was evident that he had an overall positive perspective related to seeing pictures and other interventions aimed at orienting him to his early acute care phase. Verbal and written accounts were used to help fill in Jason’s memory gaps. Family members and friends gave Jason their verbal accounts concerning the severity of his condition during the early acute care period. They also shared one picture of him in the ICU, which was meant to orient him to what he looked like after his injury. Lastly, written tests which Jason took in rehabilitation were shared and used to fill in his memory gaps on how different his thought processes were in the early acute care period.

Jason recalled how he initially relied heavily on stories from family and friends to piece together the memory gaps from his early acute care phase. However, this was initially distressing:

> Well, it[‘s] just that I remember people telling me stuff and it just didn’t click. I was in this fog and it just didn’t seem real to me or make any sense. It just felt like it was all a dream or something…. Yeah, it’s really weird thinking about it, just because, like, you don’t think of yourself as a kid that just had a traumatic brain injury, that’s sort of, you know, handicapped.

These statements appear to indicate that hearing about the severity of his condition from others was somewhat distressing for Jason. Their statements lacked context because he had no memory
of that time. The stories were subjective and lacked a needed objectivity that Jason could relate to. Jason was able to find this objectivity in the following two interventions used to orient him to his early acute care phase.

Careful analysis of Jason’s two interviews revealed that having a picture from his acute care period was one of the most beneficial interventions used to fill in his memory gaps:

I think having just one picture is the best idea, just so I can know what it was like, but I don’t have to try and imagine how terrible it actually was.... So, yeah, I think having just one picture, and not a whole collage of, you know, the bad times, is a good idea…. It’s sort of- it’s unreal that I actually was in that state. You know, just because I saw the picture with all the bandages on my head and all the tubes connected to it… [it was like] bragging rights?

This is very important because without having the physical evidence of a picture, Jason only had his imagination to fill in his memory gaps. However, the picture helped give him a better understanding of his condition. The picture also provided context to the verbal accounts he received from family and friends. The picture personalized the experience for Jason, and helped make the story his own.

Many of the participants in the original study recalled that some of their first memories after their severe TBI was feeling like they were waking up from a bad dream. These participants stated that their family, friends, and healthcare providers were telling them of their injuries, but these stories lacked personal context because the participants had no memory of their injuries. Hearing about their condition felt like hearing someone else’s story. The above statements
clearly show that Jason believed having a picture from his acute care period solidified the stories he was hearing from those around him. It helped turn what would have been a distressing experience into a positive experience. However, it is important to consider Jason’s strong feelings against having multiple photographs from his acute care period. He felt that multiple pictures would have been distressing, and he was very thankful that there was only one picture from the ICU.

One last intervention used to orient Jason to his early acute care phase was comparing written tests he had taken during his early acute care phase to those same tests taken much later in his rehabilitation:

> When I saw [the tests from the early acute care phase], I was just really amazed at how completely sort of blank I was… You’re like, “Well how could I get that wrong?” Because you know that you could’ve done that right back [before your injury], or now that you’re more healed…

Jason initially felt that it was strange to see tests from his early acute care period that he did not remember taking, and it was difficult to be confronted with the cognitive deficits he suffered. However, Jason noted in his second interview that he was grateful for the healthcare providers showing him these tests. The tests helped him see the progress he made and gave him a better outlook on his condition. Seeing the personal progress he made, as well as how he compared to others with severe TBI was therapeutic for Jason.

*Negative Experience*
Careful analysis of Christine’s experience revealed that she had a more negative reaction to the verbal and written accounts that family members’ used to fill in her memory gaps from her early acute care period.

Christine had a very difficult time coming to terms with the stories her family and friends told her about the severity of her condition. She felt like these stories lacked a personal context because she had no memory of the injury. She felt like she was hearing stories about another girl who was in an accident. Christine also had to deal with delusional memories, which are defined as, “Nightmares, hallucinations, dreams, or the sense that someone [is] trying to harm the [individual sensing these feelings]… (Colville et al., 2008).” It is important to note that patients often believe delusional memories to be factual, and this disconnect between perception and reality can lead to post-traumatic stress (Colville et al., 2008). Christine describes her delusional memories as:

Like, there were things that I thought I remembered, and my parents would be like, ‘No, that didn’t happen.’ Like, I thought my parents had this hotel room at the hospital, and all this weird stuff.

When Christine was asked about how she dealt with her delusional memories, she stated it was:

Weird, really weird. And not only that, but to not know things, and have to have people tell you, “Oh, you had this happen to you, that happened to you,”—like, I didn’t know any of my injuries, if people wouldn’t have told me. It was like, scary; someone could’ve beat me—someone could’ve hurt me, but then told me I
was in a car accident, because I had no clue. No memory of anything about it: my car accident, of anything of that day. I don’t know, it’s just weird.

The above statements shed light on the inner turmoil Christine dealt with in making sense of her memories. It was an experience unlike anything she had ever gone through before. She also speaks further on how difficult it was to learn about her injury from someone else. The memory gaps were frightening. She was forced to believe what others were saying because she had no other choice. This experience was very disturbing for Christine.

Christine also had a distressing experience talking to the trauma surgeon about the severity of her condition. The doctor tried to help fill in parts of Christine’s memory gaps, but the information proved to be traumatic. He mentioned that she almost died several times, and this was difficult for Christine to hear. She began to cry when the reality of her critical condition sank in:

[My surgeon,] he was talking to me about it—my surgery I had—and my spleen was bleeding—and telling me everything. And I remember him saying, like, “They had to give you five units of blood, and it just kept running through you.” And I remember him saying, like, “You were leaving us, Christine,” … I was finally starting to realize it was way worse than I had any idea. And then I remember I started crying…
Knowing the exact details of her injuries and how close she came to dying were negative experiences for Christine. Through careful analysis, it is evident that verbal accounts from her trauma surgeon were not immediately perceived as beneficial for Christine.

Other interventions used to fill in Christine’s memory gaps included journals written by her parents, boyfriend, and her best friend and friend’s family. Each individual wrote different things. Her boyfriend, best friend, and her best friend’s family mostly wrote notes of encouragement. However, her parents chronicled the events Christine went through during her early acute care period. Christine eventually read the journals, but it was not easy:

...It’s just hard, having to listen to someone else tell you what happened... The most I get from it is...feeling really cared about and loved. But I don’t feel like...I’m talking about me. It feels like I’m telling a story about some girl that was in a car accident. It doesn’t feel like it’s me. It’s weird.

The above statement shows that the journal lacked sensitivity in filling in Christine’s memory gaps. Something was missing from the journal, and it appeared to be pictures. When Christine was asked about whether she had pictures from her early acute care period, she responded:

At [name of acute care hospital] there was none. Like, my godmother said that she thought... almost to take a picture, but she thought... it would’ve been morbid at the time, because they didn’t know if I was going to make it. So they didn’t take pictures.
When asked if she wished there were pictures, she responded:

I wish I could see what everything looked like. It would make it feel more real. It’s really hard, like, for me to connect everything. I feel like, I don’t know, it’s hard for me to connect my life now with my life before. I feel like there’s a big gap missing. And there kind of is, because I don’t remember anything, really. And even when I started remembering things, a lot is really foggy for a few months.

Clearly, Christine felt that the lack of pictures impaired her recovery. She believed pictures would have helped connect the person she was before her injury to the person she was after. Without pictures to help her truly understand her condition, she felt there may always be gaps in her understanding from that period of time.

The above examples show that Christine had a negative experience concerning the interventions used to fill in her memory gaps. Her responses suggest the interventions were almost traumatic. Without pictures, the interventions were unsuccessful in therapeutically filling in Christine’s memory gaps from her early acute care period.

**Mixed Experience**

Lastly, careful analysis of Janice’s interviews showed that she experienced mixed emotions in regards to the interventions used to fill in her memory gaps. Janice reported that verbal accounts from family and friends, as well as a written journal from her mother were used to fill in her memory gaps. These interventions were neither traumatic nor positive. Her emotions and feelings regarding the interventions were almost equivocal. When asked about how she responded to the verbal accounts from family and friends, she responded:
Well… I’m kind of accepting it, I just take it for what it is, ‘cause like these are people who, to me, obviously aren’t going to lie about what I’ve forgotten… I just take it as what happened, that I was in whatever, coma state, so… I trusted them.

Janice took her family and friend’s accounts at face value. She accepted what they said because she had no personal recollection of her injury. She also believed there was no reason for her family or friends to lie. Therefore, the only solution Janice believed she had was to believe what others told her.

The second intervention used to orient Janice to her early acute care phase was a journal written by her mother. When the interviewer investigated how Janice responded to reading about the severity of her condition, she noted she had not read the journal yet:

… I haven’t read it yet, but… I’m going to read that eventually, but I’m not at a place where I’m ready to do that yet I guess.

It is important to note that Janice had difficulty accepting her limitations following her TBI. She resented the fact that she initially had to use assistive devices such as a wheelchair and handrails in her bathroom. She longed to be “normal” because she did not want to be treated differently. The same desires to be “normal” resurfaced when Janice returned to school following her injury. Many of the teachers offered special assistance to Janice, but she disliked being treated differently than her classmates. The extra assistance made her feel like an outsider. Therefore, reading about her accident and the severity of her condition would have brought back many of these difficult memories. Therefore, she wanted to wait until she had more time to heal
emotionally. She felt it was important to keep the journal because it would help her reflect on the progress she made:

…When I do get around to reading it, I will be amazed at how far I’ve come and that definitely is an invaluable tool… I think that would be great.

Although no pictures were used to help orient Janice to her acute care period, she was asked about her thoughts on pictures. Janice indicated that she believed having pictures to supplement the journal would be the best option:

Well I guess the same thing, like show… pictures, but also with that reading the diary like, a scrapbook would be the ultimate thing, I guess.

Even though Janice was not ready to read her journal, she still felt having pictures would have been a great asset. She felt that pictures would have been a helpful supplement to the journal, even though she was not ready to read the journal yet.

Through careful analysis of Janice’s interviews, it is easy to see her mixed feelings regarding the interventions used to fill in her memory gaps. She had no difficulties accepting any verbal accounts from family and friends. However, something was missing from these accounts. Her mixed perspective can also be seen in her views surrounding her journal. Although she felt the journal would be helpful in the future, the painful memories of her recovery prevented her from utilizing it. However, it is important to note that even though Janice was not able to read her journal, she believed having pictures to supplement would be helpful.
The results of this secondary analysis indicate that children’s responses to interventions used to fill in their memory gaps are influenced by how the interventions affect the child’s sense of self. In other words, the success of the intervention depends on how well it connects the child’s perception of themselves before the injury to who they are after the injury (Moldover, Goldberg, & Prout, 2004). Research indicates that it is important for those with TBI to be able to connect who they were before the injury to who they are after (Moldover et al., 2004). The connection helps patients cope with the effects of the injury (Moldover et al., 2004). Research has taken place to determine why it is so important for those with TBI to connect who they were before the injury to their sense of self after the injury (Cantor et al., 2005). An expanded definition of the self-discrepancy theory has been used to try to explain this phenomenon. Traditionally the SDT deals with inconsistencies in three domains: the actual self (who the individual believes they are), the ideal self (who the individual would like to be), and the ought self (what the individual believes others think they should be based on social norms) (Cantor et al., 2005). However, Cantor et al (2005) looked at expanding the definition of the SDT with individuals with TBI to include inconsistencies in the individual’s beliefs on their “preinjury self” and their “current self”. This study showed that inconsistencies between the preinjury self and current self leads to negative psychological outcomes such as depression and anxiety (Cantor et al., 2005).

Although Cantor’s study dealt with adults, it is reasonable to extrapolate the findings for consideration in the pediatric population. The expanded SDT helps explain many of the negative responses obtained in the interviews. A common theme among the negative responses was how the interventions lacked the ability to personalize the injury for the participant. This lack of
personalization was distressing because it prevented the participant from connecting their preinjury self to their current self (Cantor et al., 2005).

Analysis of the interviews showed that pictures of the children during their early acute care period was the biggest indicator of how the child would respond to interventions used to fill in their memory gaps. Pictures were associated with positive perspectives because they helped provide physical evidence of the injury. This physical evidence helped connect the preinjury self to the current self. Therefore, it is important to remember to take pictures of children with severe TBI during their early acute care period. They may choose to not view the pictures, but it is important for children to have the option. Without pictures, children may respond very negatively to verbal and written interventions meant to fill in their memory gaps.

**Limitations**

Given this is a secondary analysis, the findings should only be considered preliminary. A prospective study should be conducted with this population to better understand a broader range of responses to filling in memory gaps with diaries, emails, photos, or other information. A prospective study will allow more detail to be collected from children who find such approaches helpful versus those who find such information distressing or have mixed feelings. There may be information that was not able to be collected in the original study that would be helpful in fully understand this phenomenon.

**Conclusion**

In conclusion, filling in children’s memory gaps is very important following severe TBI. However, the manner in which this is accomplished is critical. Although verbal accounts and
written stories (i.e. journals, letters, care sites) are helpful, this secondary analysis showed that these interventions can be distressing without pictures to supplement the information. Therefore, it is important for parents of children with severe TBI to be careful to take pictures of their children during their early acute care phase. Although the children may decide to not use the pictures, it is important for them to have the option. The incorporation of pictorial, written, and verbal information can help children connect their preinjury self to their current self. Making this connection is important because it can help children with severe TBI come to terms with changes and losses after their injury.

**Implications for nursing**

This secondary analysis provides valuable information for nurses working in pediatric ICUs or any setting where nurses deal with children in their early acute care phase following TBI. Nurses can use the information from this study to promote the use of pictures and other narrative accounts to help fill in children’s memory gaps following TBI. It can be difficult for parents to know how to properly care for their children while they are in the hospital. Nurses can help ease this anxiety by educating parents on the importance of caring for their children through chronicling the events of their early acute care period via pictures and written accounts. The information from this study can be used to promote comprehensive and holistic care for the patient, as well as care for the entire family.
References


