

Caregiver perceptions of home, school, and community environmental barriers
experienced by children with traumatic brain injury

Undergraduate Honors Research Thesis

Presented in Partial Fulfillment of the Requirements for graduation “with Honors
Research Distinction in Speech and Hearing Science” in the undergraduate colleges of
The Ohio State University

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May 2022

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Introduction

Traumatic brain injury (TBI) is a large contributor to mortality and disability for young people. A TBI is defined as a bump, blow, or jolt to the head that disrupts brain functioning (CDC, 2018). In the U.S., over 800,000 children and adolescents are hospitalized for TBI annually (Chen et al., 2017). Children aged 0-4 years and 15-19 years are among the most likely to have a TBI-related emergency department visit or hospitalization (CDC, 2015; Taylor et al., 2017).

TBI Severity and Common Causes

The most common tool to assess TBI severity is the Glasgow Coma Scale (GCS), a neurologic scale that measures eye opening, verbal response, and motor response (Teasdale, 1974). Considering the best available score within 24 hours of injury, a GCS score between 13-15 indicates mild TBI, a GCS score of 9-12 indicates moderate TBI, and a GCS score of 3-8 indicates severe TBI (CDC, 2018). Another category, complicated-mild, reflects both a GCS score of 13-15 and neuroimaging abnormalities such as skull fracture or intracranial bleeding (Levin et al., 2008; Gerard-Morris et al., 2009). There is some evidence that children with complicated-mild TBI have poorer cognitive outcomes than children without neuroimaging abnormalities (Levin et al., 2008). Children with mild TBI might undergo a brief loss of consciousness, and often struggle with headaches, nausea, vomiting, sensitivity to light and sound, and difficulties with concentration and memory for weeks to months (Howarth, Blackwell, & Ono, 2016). Children with moderate and severe injuries might experience altered consciousness (e.g. coma, unresponsive wakefulness, or a minimally-

conscious state) for up to 24 hours (CDC, 2015), and tend to experience disorientation, confusion, and post-traumatic amnesia for a longer period (CDC, 2015; Howarth, Blackwell, & Ono, 2016). Mild injuries comprise around 80% of pediatric TBI cases, while moderate and severe TBI represent 20% of injuries (Rivara et al, 2011; Saatman et al., 2008). Due to the higher incidence of mild TBI, the population burden of disability following TBI is largely driven by mild injuries; however, the proportion of children with disabilities due to brain injury is much greater among those with moderate or severe TBI (Rivara et al., 2012b).

Causes of pediatric TBI vary widely, but the most common mechanisms include falls, sport-related injuries, being struck by an object, and motor vehicle accidents. Falls are the most frequent cause of TBI among children between 0-4 years, while the proportion of pediatric TBI due to motor vehicle accidents increases with age (Taylor et al., 2017; Chen et al., 2017). While motor vehicle accidents contribute to all types of TBI, traffic-related injuries are a frequent mechanism among children who sustain severe injuries (Slomine et al., 2006; Catroppa et al., 2008), and children injured in motor vehicles are more likely to have resulting physical disabilities (Wechsler et al., 2005). The distribution of pediatric TBI is skewed by gender, with males making up around 60% and females making up 40% of cases (Chen et al., 2017). Abusive head trauma contributes to moderate and severe TBI, most frequently in young children (CDC, 2018).

Common problems following pediatric TBI

As the brain is a complex and vital organ, TBI impacts many aspects of functioning, including physical capabilities, cognition, mental health, and social skills (Howarth, Blackwell, & Ono, 2016). Children receive educational, physical, and mental health services due to TBI at much higher rates than children with orthopedic injury (OI), indicating that brain injury uniquely impacts a child's functioning (Rivara et al., 2012b). Around 13-15% of children with mild and up to half of children with moderate and severe TBI report a decrease in their quality of life (Rivara et al., 2012b; Zonfrillo et al., 2014). For the developing brain, TBI can disrupt a child's ability to learn and remember. For example, Taylor and colleagues examined cognition 1½ months after injury and found that children with TBI had lower performance than children with orthopedic injury on measures of working memory, verbal fluency, pragmatic language and judgment, and executive function (2008). Despite some recovery in cognitive functioning, children with moderate or severe TBI continue to have higher rates of academic need compared to an OI comparison group almost seven years post-injury (Kingery et al., 2017). Pediatric TBI often results in difficulties with attention and executive function (Taylor et al., 2008; Kurowski et al., 2011), which can impact cognitive flexibility, decision-making, and social interaction. Navigating a condition like TBI, where the injury can have a diverse array of consequences and recovery is variable, can be stressful for families (Wade et al., 2006). Unmet health care needs or limited resources compound the challenges of injury, resulting in caregivers reporting greater worry and interference with daily life (Aitken et al., 2009).

Factors contributing to recovery rate and trajectory

A considerable number of factors contribute to a child's recovery following TBI. Greater injury severity is often linked to worse outcomes in physical, emotional, social, and school functioning. In a study by Slomine and colleagues (2006), children with no reported issues in the above-named areas were significantly more likely to sustain less severe, fall-related injuries than vehicle-related injuries. With a larger area of the brain affected, diffuse injury or injury requiring surgical intervention is associated with greater impairment in behavioral and cognitive performance (Catroppa et al., 2008). The cognitive and behavioral difficulties associated with more severe injury may be due to the limited amount of healthy brain tissue to support plasticity and/or recovery processes (Anderson et al., 2010).

Age at injury also moderates a child's recovery, with younger children generally showing more vulnerability to long-term neurobehavioral impacts whether they have a diffuse or localized injury. In a study by Anderson and colleagues (2010), children with localized early brain injury took cognitive assessments covering intelligence, language, visuospatial skills, attention, memory, executive function, and processing speed. There was a significant discrepancy in language, visuo-spatial, attention, and executive function skills between children injured before age 2 and children injured over age 7, with the former group recording more global and severe cognitive deficits. The authors concluded that even though younger age is typically associated with greater neuroplasticity, "there was little evidence that this group had increased potential for reorganization of function" (p. 724). This finding aligns with an earlier study by Anderson

and Moore (1995), which found that children with TBI had greater mean verbal IQ than mean performance IQ scores post-injury. Verbal IQ measures crystallized skills that depend on existing knowledge, while performance IQ measures more fluid skills based on immediate processing; therefore, the researchers concluded that brain injury has a greater impact on fluid than crystallized skills. However, if a child has not had the opportunity to build a strong foundation of knowledge, brain injury might damage the general cognitive processes needed to do so (Catroppa et al., 2008). The relationship between age and long-term neurobehavioral effects of TBI is not exactly linear, as more recent evidence suggests that children injured between 7-9 are also susceptible to cognitive difficulties, but the early vulnerability model remains valid when comparing late childhood (10+ years) to early childhood injury (Crowe et al., 2012).

In children, recovery from TBI is overlaid on typical cognitive development, and so adverse symptoms might not appear until a child passes certain developmental milestones. If a cerebral area is damaged before it becomes functional, then deficits will not be expected to appear until the skills for which the area is responsible would normally emerge. Accordingly, academic difficulties frequently persist or worsen over time due to increasing executive demands and diminishing environmental supports, particularly for children injured at a younger age (Ewing-Cobbs et al., 2004). Problems with social behavior might also be delayed, appearing when social situations become more complex and the developing prefrontal cortex typically starts to control emotional responses (Tonks et al., 2009). Emerging problems present a challenge for those affected by pediatric TBI, and the proportion of unmet medical, mental health, and

educational needs for complicated-mild, moderate, and severe TBI has been found to increase over time, potentially due to removal of therapy services (Fuentes et al., 2018).

In addition to individual characteristics, family dynamics can facilitate or hinder recovery. Healthy family functioning, as assessed by the General Functioning Scale (GFS) of the Family Assessment Device, is associated with better functional outcomes, possibly due to greater recognition of service needs (Slomine et al., 2006). High amounts of parental warmth and responsiveness might reduce levels of internalizing (self-directed problematic behavior) and externalizing (problematic behavior directed toward others) problems by providing regular, positive feedback that reinforces self-regulation. At the very least, these traits correlate to lower levels of behavioral problems (Wade et al., 2011). In contrast, parental negativity has been associated with higher levels of both internalizing and externalizing behavior problems. More broadly, high levels of authoritarian or permissive parenting are linked to behavioral and cognitive impairment across school, home, community, and social settings for youth with TBI (Wade et al., 2011). The physical space where a family lives also appears to influence functioning after pediatric TBI. In home environments with low enrichment (e.g. low availability of learning materials and opportunities), children with TBI have been shown to have significantly poorer long-term cognitive and behavioral outcomes than children in facilitative home environments (Wade et al., 2016).

Treatment of TBI

Care for TBI begins with management of the acute brain injury and major associated injuries. TBI-specific issues can include skull fracture, intracranial hypertension, and post-traumatic seizures (Kochanek et al., 2019). In more severe cases, children are referred to inpatient rehabilitation to manage difficulties with mobility, gross and fine motor skills, swallowing, and communication. For all severity levels, persistent cognitive, physical, and socioemotional symptoms might be managed through neuropsychological assessment and educational supports; speech, occupational, and physical therapy; and psychological counseling, respectively (Rivara et al., 2012a). In 1991, the Individuals with Disabilities Education Act (IDEA) added TBI as a specific eligibility category, qualifying children with TBI for special education services implemented through an Individualized Education Plan (IEP; CDC, 2018). To facilitate the return-to-learn process, public schools can provide formal educational services, such as an IEP or 504 plan, or informal education accommodations (Glang et al., 2008). While informal accommodations can involve modifying a student's schedule, altering the classroom environment, and providing assistive technology, an IEP/504 is more tailored to the student's personal academic and healthcare needs, and can implement the above-named accommodations as well as speech-language therapy, physical therapy, occupational therapy, and special education classes (CDC, 2018).

Involvement with medical providers, family dynamics, and educational and community supports contribute to the extent that cognitive, physical, and socioemotional needs are met. Unfortunately, up to 25% of children report unmet needs after a TBI

(Fuentes et al., 2018), and some studies report that more than half of children who would benefit from education, rehabilitation or mental health services do not receive them (Rivara et al., 2012b). While service needs cover a wide range, cognitive services are the most frequent unmet or unrecognized need (Slomine et al., 2006). Accordingly, at least half of children with a history of TBI have unmet academic needs 6.8 years post-injury, with greater unmet need among children with moderate or less severe injury (Kingery et al., 2017). Upon return to school, 18.5% of children with severe TBI and 1/3 of children with TBI overall do not receive any type of educational service; many more do not receive formal services like an IEP or 504 (Glang et al., 2008).

Gaps in rehabilitation care

As reported by caregivers, lack of medical or school recommendation for services, inadequate provision of educational services, and financial cost are the most common reasons for unmet needs (Slomine et al., 2006). Consequently, racial, economic, and educational disparities exacerbate unmet and unrecognized needs in children with TBI. Children whose families earn more than \$50,000 annually are more likely to have their physical needs met (Fuentes et al., 2018), and children with no needs or met needs are significantly more likely to have private health insurance (Slomine et al., 2006). Up to 12 months post-injury, children with unrecognized needs were 47% more likely to be nonwhite, and their caregivers were more likely to report less than a high school education and abnormal family functioning (Slomine et al., 2006). Resolving physical, social, and emotional needs is important for recovery, as caregivers who report their child with TBI as having no needs or met needs describe

better quality of life 12 months post-injury, compared to children with unmet or unrecognized needs (Slomine et al., 2006).

Overall, communication disconnect between caregivers, medical providers, and educators underly many unmet and unrecognized needs, and identifying barriers and facilitators to adequate care is essential to improve outcomes for children with TBI. In healthcare, barriers to attending follow-up appointments might explain some of these needs, as one study found that only around 50% of children with TBI attend scheduled follow-up appointments within the first two years after injury (Spaw et al., 2018). Barriers to follow-up care commonly include the family reporting no identified needs, schedule conflicts, and a lack of resources (Lever et al., 2019). Conversely, facilitators to follow-up appointments include good hospital experiences, identified need, sufficient resources, well-coordinated appointments, and the provision of counseling and support (Lever et al., 2019). Children with mild TBI were more likely to receive academic accommodations if they had a follow-up visit compared to those without follow-up (Grubenhoff et al., 2015). In school, parental requests and hospital-to-school transition services facilitated receipt of formal educational services (Glang et al., 2008). While injury age and severity cannot be altered once an injury occurs, a growing body of evidence demonstrates that environmental characteristics of the family, school, and the healthcare system shape outcomes following pediatric TBI, and engaging with people within these settings is central to resolving gaps in cognitive, physical, and socioemotional care. To address these gaps in our knowledge, the proposed aims of this research were the following:

1. Describe the home, school, and community environmental barriers experienced by children with TBI.
2. Examine how demographic and injury characteristics associate with the environmental barriers reported by caregivers.

Objectives

This project intends to describe home, school, and community environmental barriers experienced by children with TBI, as well as investigate the relationship between environmental barriers, demographic, and injury characteristics. This project represents a portion of a larger research study that directly engaged caregivers and medical professionals to describe their experiences related to pediatric TBI. The long-term goal of the study is to identify methods that would better meet the needs of children with TBI based on stakeholder perspectives. Given the importance of environmental factors in pediatric TBI outcomes, examining caregivers' perceptions of barriers could further define specific areas of need or identify targets for future research.

Methods

Participants

In fall 2019, this project was approved by review boards at Nationwide Children's Hospital and The Ohio State University in Columbus, Ohio. Participants included 19 caregivers who had children admitted to the inpatient rehabilitation unit at Nationwide

Children's Hospital. Families were included if 1) the child sustained a complicated-mild to severe TBI before the age of 19; 2) the child was between the ages of 1-25 at the time of interview; 3) at least 6 months elapsed between the injury and interview, and 4) the caregiver was a conversational English speaker. Exclusion criteria included 1) non-accidental mechanism of TBI, 2) severe developmental delay, seizure disorder, psychiatric disorder, or neurologic disease diagnosis before injury, or 3) brain injury that occurred before 1 year of age.

Research Activities

After caregivers provided informed consent, they participated in semi-structured phone interviews, which included prompts regarding caregivers' perspectives on areas of care such as transitioning from the hospital to home, returning to school, education received about their child's injury, and suggestions that might have improved care. Caregivers were also given the opportunity to provide demographic information (age, occupation, level of education, household income) and to describe the child's injury (mechanism and age at injury).

The interview included questions from the *Child & Adolescent Scale of Environment* (CASE; Bedell, 2011), a multidimensional scale that addresses physical, attitudinal, and socioemotional problems their child might experience. The CASE consists of 18 prompts, which can be organized into the following categories: school, home, community, home and community, and other. The CASE examines the perceived impact, not frequency, of environmental problems encountered by children with a range of chronic conditions/disabilities, most frequently TBI. In a study of over 400 children,

the CASE demonstrated high test-retest reliability and internal consistency, and closely correlated with measures of participation restriction and health problems (Bedell, 2015).

Data Analysis

Each CASE item was rated on a 4-point scale: 0 = Not Applicable; 1 = No problem; 2 = Little Problem; 3 = Big Problem. Demographic variables considered in our analyses were: caregiver age, caregiver level of education, and annual household income. Injury-related variables considered in our analyses were: severity, mechanism, age at injury, school age group at injury, time since injury, and length of hospital stay. The following characteristics were coded as ordinal variables: annual household income, caregiver level of education, household income, injury severity, mechanism of injury, time since injury, and school age group at injury. Caregiver age, child age at injury, child age at interview, and length of hospital stay were treated as continuous variables. CASE responses, injury characteristics, and demographic information were uploaded into IBM SPSS Statistics (version 28.0.1.0). Descriptive statistics for caregiver age, child age at injury, child age at interview, and length of hospital stay were calculated. Because the data contains both ordinal and continuous variables, Spearman's correlation coefficient was selected to examine the relationship between CASE responses and injury and demographic characteristics. Prior to correlational analysis, scatterplots were derived for each pair of variables, and each group displayed a monotonic relationship, fitting the assumption criteria for Spearman's rho. SPSS

calculated Spearman's correlation coefficients between the 18 CASE categories and 10 demographic and injury variables.

Results

Table 1 shows demographic and injury-related characteristics of the included participants. The majority of caregivers were mothers (89.47%), though one grandmother and one father completed interviews. Mean caregiver age was 40.35 years. Caregivers from a variety of education levels and household incomes were represented; however, 73.86% of caregivers did not have a bachelor's degree and reported annual household income below \$80,000.

The majority of children with brain injury in this sample were male and injured in a motor vehicle collision (both 89.47%). Their mean age at injury was 11.40, but ranged from 2 years and 7 months to 19 years. The majority of children sustained a severe injury (84.21%), with one child experiencing complicated-mild and two experiencing moderate injury. Participants spent an average of 53.95 days in the hospital with considerable variability (SD = 30.83, range = 14.00-111.00). While it seems likely that injury severity might correlate with length of hospital stay, the participants with moderate TBI had the two longest hospital stays (103 and 111 days).

Table 1. Demographic and injury characteristics.

Demographic information	N (%)
Caregiver level of education	
High School/GED	6 (31.57)
Associate's	8 (42.10)
Bachelor's	3 (15.79)
Master's	2 (10.52)

Annual household income	
Unknown	2 (10.5)
<\$39,000	4 (21.1)
\$40,000 - 59,999	3 (15.8)
\$60,000 - 79,999	7 (36.8)
\$80,000 - 99,999	2 (10.5)
>\$100,000	1 (5.3)

Caregiver age	
Mean	40.35
Standard Deviation	4.56811
Range	32.00 - 52.00

Caregiver relationship	
Mother	17 (89.47)
Father	1 (5.26)
Grandmother	1 (5.26)

Sex of TBI Survivor	
Male	17 (89.47)
Female	2 (10.53)

Injury variables	N (%)
Age at injury	
Mean	11.40
Standard Deviation	4.76989
Range	2.60 - 18.10

School age group at injury	
Unassigned	1 (5.26)
Preschool	5 (26.32)
Elementary	3 (15.79)
Middle School	6 (31.58)
High School	4 (21.05)

Severity of Injury	
Mild-Complicated (GCS 13-15 with evidence of intracranial lesion/bleed)	1 (5.26)
Moderate (GCS 9-12)	2 (10.52)
Severe (GCS 3-8)	16 (84.21)

Length of hospital stay (days)	
Mean	53.95
Standard Deviation	30.83
Range	14.00 - 111.00
Mechanism of injury	
MVA	17 (89.47)
Struck by object	1 (5.26)
Fall	1 (5.26)
Time since injury	
1 – 4.9 years	13 (68.42)
5 – 7.9 years	3 (15.78)
>8 years	3 (15.78)
Age at interview	
Mean	17.19
Standard Deviation	3.05921
Range	10.70 - 21.60

CASE Responses

The CASE responses of all participants are displayed in Table 2. Due to small sample size, responses indicating a *little problem* or *big problem* on the CASE were added together to determine problems of any kind that families reported. Participants identified problems in all CASE categories, with at least three participants reporting problems for each question. However, participants reported the highest number of problems in the following CASE categories:

1. Family stress (15/19, 78.95%)
2. Inadequate or lack of programs and services at school (10/19, 52.63%)
3. Inadequate or lack of family finances (9/19, 47.39%)

4. Inadequate or lack of programs and services in the community or neighborhood
(9/19, 47.39%)
5. Inadequate or lack of support from school (8/19, 42.10%)
6. Inadequate or lack of support from community (8/19, 42.10%)

The only CASE section where zero participants reported a *big problem* was inadequate or lack of information about diagnosis or condition or intervention approaches (e.g., educational, rehabilitation or medical).

Table 2. Responses to CASE (Child and Adolescent Scale of Environment), reported as n (%).

CASE Question	No Problem	Little Problem	Big Problem	Not Applicable
<i>Home</i>				
Design and layout of home	15 (78.95)	1 (5.26)	3 (15.79)	0
Inadequate or lack of assistive devices or equipment	12 (63.16)	3 (15.79)	1 (5.26)	3 (15.79)
Inadequate or lack of family finances	10 (52.63)	5 (26.32)	4 (21.05)	0
Family stress	4 (21.05)	8 (42.10)	7 (36.84)	0
<i>Home and Community</i>				
Inadequate or lack of transportation	15 (78.95)	3 (15.79)	1 (5.26)	0
Inadequate or lack of assistance from people at home or in the community or neighborhood	15 (78.95)	2 (10.53)	1 (5.26)	1 (5.26)

Community				
Design and layout of community buildings	14 (73.68)	2 (10.53)	2 (10.53)	1 (5.26)
Inadequate or lack of support from community	11 (57.89)	5 (26.32)	3 (15.79)	0
Problems with people's attitudes toward your child in the community or neighborhood	13 (68.42)	3 (15.79)	2 (10.53)	1 (5.26)
Inadequate or lack of programs and services in the community or neighborhood	10 (52.63)	4 (21.05)	5 (26.32)	0
Crime or violence in the community or neighborhood	15 (78.95)	1 (5.26)	2 (10.53)	1 (5.26)
School				
Design and layout of school or work	16 (84.21)	1 (5.26)	2 (10.53)	0
Inadequate or lack of support from school	11 (57.89)	4 (21.05)	4 (21.05)	0
Problems with people's attitudes toward your child at school or work	12 (63.16)	5 (26.32)	2 (10.53)	0
Inadequate or lack of assistance from people at school or work	12 (63.16)	4 (21.05)	3 (15.79)	1 (5.26)
Inadequate or lack of programs and services at school	9 (47.37)	6 (31.58)	4 (21.05)	0
Other				
Problems with government agencies and policies	15 (78.95)	2 (10.53)	2 (10.53)	0

Inadequate or lack of information about your child's diagnosis or condition or intervention approaches (e.g., educational, rehabilitation or medical)	16 (84.21)	3 (15.79)	0	0
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Injury characteristics and CASE

Age at injury showed significant negative correlations with problems regarding school support and community services ($r=-.463$, $p=0.046$), suggesting that children injured at an older age were more likely to receive adequate school support and community services (see appendix for correlation table).

Injury severity negatively correlated with CASE responses for design/layout of buildings in the community ($r=-.544$, $p=.016$), assistance ($r=-.535$, $p=.018$) and support ($r=-.468$, $p=.043$) from people in the community, community crime or violence ($r=-.5$, $p=.029$) and lack of information on diagnosis ($r=-.623$, $p=.004$). These results indicate that children with more severe injury were less likely to encounter problems in these areas. Time since injury was positively correlated with family stress ($r=.458$, $p=.049$), indicating that family stress increased as time post-injury increased. Length of inpatient stay was negatively correlated with injury severity just above levels of statistical significance ($r=-.452$, $p=.052$), implying that children with severe injuries were slightly more likely to have a shorter hospital stay.

Demographics and CASE

Caregiver age was negatively correlated with problems surrounding support at school ($r=-.492$, $p=.045$), assistance from people at school ($r=-.673$, $p=.003$), school services ($r=-.758$, $p<.001$), diagnosis information ($r=-.539$, $p=.026$), and family stress ($r=-.52$, $p=.032$). These correlations indicate that as caregiver age increased, caregivers were less likely to report problems related to school services or support, diagnosis information, or family stress.

Annual household income negatively correlated with problems with school support or community services ($r=-.470$, $p=.042$). This indicates that as household income went up, caregivers were less likely to report issues obtaining school support or community services. Inadequate family finances did not significantly correlate with annual household income, but rather with caregiver education level ($r=-.577$, $p=.01$). This indicates that as caregiver education increased, participants were less likely to report problems with inadequate family finances independent of annual household income.

Discussion

This study examined caregiver perceptions of home, school, and community barriers experienced by their children with TBI. Caregivers reported high levels of barriers related to family stress and finances, as well as lack of services and support in the school and community. These findings are consistent with a 2013 scoping review that listed negative attitudes/stigma, inaccessible physical environments, and

inadequate or lack of services, policies, and support from service providers as the most common environmental barriers for children with disabilities (Anaby et al., 2013). More recently, a study specific to childhood TBI found that caregivers reported schedule conflicts and lack of resources (including insurance coverage, transportation, or childcare support) as major barriers to medical follow-up appointments (Lever et al., 2019). These factors are consistent with the high level of home and community environmental barriers that caregivers in this sample reported. As the majority of children in this sample had severe TBI, it was not surprising that caregivers struggled with family stress and inadequate family finances, as caregivers of children with more severe injury are more likely to miss work (Aitken et al., 2009) and report that a TBI results in greater family burden (Wade et al., 2006). High caregiver burden is not only a serious issue in and of itself, but also impacts recovery. Greater family cohesion and socioeconomic status are associated with better executive function and attention (Kurowski et al., 2011), academic performance (Catroppa et al., 2008), and fewer internalizing and externalizing behavior problems (Wade et al., 2011). Caregiver and family burden represent an area of intervention with the potential to improve outcomes across different domains.

While the finding that caregivers of children with severe injury report fewer problems in the community and fewer barriers related to diagnosis information may seem counterintuitive, emerging evidence suggests that children with less severe injuries struggle in ways that can be more difficult for outsiders and educators to recognize. Children with moderate TBI have higher rates of unmet academic need

compared to children with severe injury, and lack of physical or obvious symptoms for evaluating recovery may contribute to this unmet need (Kingery et al., 2017). Children with more severe injury are also more likely to receive physical, occupational, and speech therapy evaluations (Bennett et al., 2013), and these medical providers can provide recommendations that empower caregivers to request specific services (Glang et al., 2008). Perhaps children with more severe injuries have more obvious symptoms, thus their caregivers report fewer barriers to receiving information about their child's diagnosis and in receiving supports they need in their communities and schools. It is possible that children with less severe injuries demonstrate more subtle difficulties that are more challenging for educators and people in the community to recognize. With this consideration, it was therefore surprising that, in this research, injury severity did not significantly correlate with problems in school. However, our sample included only children admitted to inpatient rehabilitation, which represent a very specific and small subset of the total number of children who sustain a TBI each year (Greene et al., 2014). Inpatient rehabilitation services may have improved school transition but not community and diagnosis barriers for children with less severe injury.

Although the association between time since injury and family stress may also appear counterintuitive, a large amount of evidence suggests that problems from TBI emerge over time, especially when an injury occurs during development. In this study, family stress increased with time since injury. This result supports research by Hawley (2003), who found that the majority of families in their sample reported new problems, particularly with cognition and maladaptive behavior, one year post-injury. A more

recent study found that unmet need among physical, self-care, cognitive, communication, and mental health domains increased in the two years following injury (Fuentes et al., 2018). Wade and colleagues found that family dysfunction among children with TBI also increased between 1 year and 4-5 years post-injury (2006), and problems in social and emotional functioning contribute highly to caregiver worry and interference in routine (Aitken et al., 2009). While the mean age at injury in our sample was 11.40 years, during late childhood, the mean age at interview was 17.19 years, during adolescence. Increasing responsibilities and demands during adolescence and young adulthood may pose additional challenges for individuals with a history of childhood TBI and their families. Childhood TBI may exacerbate problems with temper, attitude, and impulsivity (Hawley, 2003) beyond levels expected for adolescents, which can elevate family stress years after injury.

In this study, we found that as annual household income increased, caregivers were less likely to report barriers in the school and community. The relationship between greater household income and fewer problems in these categories aligns with a large body of evidence indicating that children from families with higher household incomes have better recovery outcomes. In the medical setting, children with private insurance have shown better adherence to follow-up appointments (Spaw et al., 2018), and caregivers of children without insurance or on public insurance were more likely to report lack of resources as a barrier to follow-up (Lever et al., 2019). Socioeconomic status also limits access to outpatient rehabilitation; for example, in Washington state, only 46% of outpatient rehabilitation providers accept Medicaid (Moore et al., 2016).

While the current study did not examine insurance status specifically, it is possible that caregivers of lower SES in this sample had more limited follow-up care and missed opportunities to learn about school and community modifications. As Ciccia and Threats (2015) discuss, the SES of the school district and available support services intersect with family SES to impact the outcomes of youth with TBI. Even when caregivers receive sufficient follow-up care, schools and communities in lower SES areas may not be able to provide services or support due to monetary barriers.

The present study demonstrates that older caregivers were less likely to report barriers related to school, diagnosis information, and family stress. Compared to child injury factors and SES, there is less information available on the impact of caregiver age and education level on environmental barriers to TBI recovery. However, older maternal age is associated with increased maturity, sensitivity, and responsiveness (Camberis et al., 2016). Older caregivers in this study may have also expressed these traits, helping them cope with stressors and reducing the number of barriers they reported. In this study, it was surprising that education level correlated more strongly to the CASE prompt for inadequate family finances. However, caregivers with higher educational attainment may perceive that they have sufficient finances due to greater savings or career opportunities, and the CASE may reflect this view. For children with TBI, parents with both greater SES and education tend to have more responsive and positive parent-child interactions (Lalonde et al., 2019), which could support better adjustment to school and community settings.

The high frequency of barriers reported in the school and community settings indicate that hospital-to-school transition services and care coordination would benefit children with TBI. In support of the former, Glang et al. (2008) found that students who received hospital-to-school services were 16 times more likely to receive formal educational supports. Educators often do not have training on the management of TBI and rely on guidance from parents and healthcare providers (Haarbauer-Krupa et al., 2017). This lack of awareness might explain why close to half of caregivers in this research reported inadequate school support and services. Transition-related communication between hospitals and schools could involve a social worker, rehabilitation therapist, or nurse to improve teachers' awareness of a student's injury and support academic recovery (Haarbauer-Krupa et al., 2017). Hospital-assigned care coordinators represent another opportunity to evaluate caregiver resources and address barriers to medical and educational services (Lever et al., 2019).

Given the high family stress among study participants and the negative impact of caregiver burden on recovery, researchers have developed several interventions to assist families in coping with pediatric TBI. For example, Counselor-Assisted Problem Solving (CAPS) involves online problem-solving and counseling sessions with children and their primary caregivers; this intervention has been shown to improve caregiver distress and efficacy (Wade et al., 2014) as well as decrease parent-child conflict (Narad et al., 2015). Online family counseling that focuses on problem solving could reduce family stress, particularly for caregivers with inadequate transportation or who otherwise struggle with in-person appointments.

Limitations

Several limitations of this research should be noted. First, the small sample size prevents generalizing these results to the large number of children and families affected by pediatric TBI, but instead offers a preliminary examination of environmental barriers reported by caregivers of children with TBI. In addition, the sample only consisted of participants admitted to inpatient rehabilitation, which is not typical for most children who sustain TBI. Although race is known to impact outcomes from childhood TBI (Haider et al., 2008), race was not examined in this study. While urban and rural environments may also impact the different resources available to caregivers, community type was not investigated. These gaps would be important areas for future research to consider.

Conclusions

This research describes the home, school, and community environmental barriers experienced by children with TBI and investigates how demographic and injury characteristics associate with these barriers. Similar to previous studies, we found that caregivers reported considerable barriers related to family stress and finances, as well as lack of services and support in the school and community. Caregiver age, annual household income, injury severity, injury age, and time since injury significantly associated with these environmental barriers. Therefore, it is critical for medical and educational providers to continue follow-up with all children who sustain TBI and assess caregiver resources. This care is particularly important for younger caregivers and

caregivers of lower socioeconomic status, who are more likely to encounter environmental barriers to their child's needs. Further research could investigate the efficacy of care coordination, transition supports, and family-based counseling on reducing environmental barriers faced by children with TBI.

REFERENCES

- Aitken, M.E., McCarthy, M.L., Slomine, B.S., Ding, R., Durbin, D.R., Jaffe, K.M., Paidas, C.N., Dorsch, A.M., Christensen, J.R., MacKenzie, E.J., and the CHAT Study Group; Family Burden After Traumatic Brain Injury in Children. (2009). *Pediatrics*; 123 (1): 199–206. 10.1542/peds.2008-0607
- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability and Rehabilitation*, 35(19), 1589–1598. <https://doi.org/10.3109/09638288.2012.748840>
- Anderson, V., & Moore, C. (1995). Age at injury as a predictor of outcome following pediatric head injury: A longitudinal perspective. *Child Neuropsychology*, 1(3), 187-202.
- Anderson, V., Jacobs, R., Spencer-Smith, M., Coleman, L., Anderson, P., Williams, J., Greenham, M., & Leventer, R. (2010). Does Early Age at Brain Insult Predict Worse Outcome? Neuropsychological Implications. *Journal of Pediatric Psychology*, 35(7), 716–727. <https://doi.org/10.1093/jpepsy/jsp100>
- Bedell, G. (2011). The Child and Adolescent Scale of Environment

(CASE): Administration and scoring

guidelines. <http://sites.tufts.edu/garybedell/measurement-tools/>

Bedell, G., & McDougall, J. (2015). The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic conditions.

Developmental Neurorehabilitation, 18(6), 375–382.

<https://doi.org/10.3109/17518423.2013.855273>

Bennett, T. D., Niedzwecki, C. M., Korgenski, E. K., & Bratton, S. L. (2013). Initiation of physical, occupational, and speech therapy in children with traumatic brain injury.

Archives of physical medicine and rehabilitation, 94(7), 1268–1276.

<https://doi.org/10.1016/j.apmr.2013.02.021>

Brasure, M., Lamberty, G.J., Sayer, N.A., Nelson, N.W., MacDonald, R.,

Ouellette, J., Tacklind, J., Grove, M., Rutks, I.R., Butler, M.E., Kane, R.L., & Wilt,

T.J.. (2012) *Multidisciplinary Postacute Rehabilitation for Moderate to Severe*

Traumatic Brain Injury in Adults. Agency for Healthcare Research and Quality

(US): Comparative Effectiveness Reviews, No. 72.) Table A, Criteria used to classify TBI severity.

<https://www.ncbi.nlm.nih.gov/books/NBK98999/table/executivesummary.t1/>

Camberis, A.-L., McMahon, C. A., Gibson, F. L., & Bovin, J. (2016). Maternal age,

psychological maturity, parenting cognitions, and mother-infant interaction.

Infancy, 21(4), 396-422. <https://doi.org/10.1111/infa.12116>

Catroppa, C., Anderson, V. A., Morse, S. A., Haritou, F., & Rosenfeld, J. V. (2008).

Outcome and predictors of functional recovery 5 years following pediatric traumatic brain injury (TBI). *Journal of Pediatric Psychology*, 33(7), 707–718.

<https://doi.org/10.1093/jpepsy/jsn006>

Centers for Disease Control and Prevention. (2015). *Report to Congress on*

Traumatic Brain Injury in the United States: Epidemiology and

Rehabilitation. National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.

Centers for Disease Control and Prevention. (2018). *Report to Congress: The*

Management of Traumatic Brain Injury in Children, National Center for Injury

Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.

Chen, C., Shi, J., Stanley, R. M., Sribnick, E. A., Groner, J. I., & Xiang, H. (2017). U.S.

Trends of ED Visits for Pediatric Traumatic Brain Injuries: Implications for Clinical

Trials. *International journal of environmental research and public health*, 14(4),

414. <https://doi.org/10.3390/ijerph14040414>

Ciccia, A. H., & Threats, T. (2015). Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: emerging concepts identified through modified narrative review. *International journal of language & communication disorders*, 50(4), 436–451.
<https://doi.org/10.1111/1460-6984.12153>

Crowe, L. M., Catroppa, C., Babl, F. E., Rosenfeld, J. V., & Anderson, V. (2012). Timing of Traumatic Brain Injury in Childhood and Intellectual Outcome. *Journal of Pediatric Psychology*, 37(7), 745–754. <https://doi.org/10.1093/jpepsy/jss070>

Ewing-Cobbs, L., Barnes, M., Fletcher, J.M., Levin, H.S., Swank, P.R., & Song, J. (2004) Modeling of Longitudinal Academic Achievement Scores After Pediatric Traumatic Brain Injury, *Developmental Neuropsychology*, 25:1-2, 107-133, DOI: [10.1080/87565641.2004.9651924](https://doi.org/10.1080/87565641.2004.9651924)

Fuentes, M. M., Wang, J., Haarbauer-Krupa, J., Yeates, K. O., Durbin, D., Zonfrillo, M. R., Jaffe, K. M., Temkin, N., Tulsky, D., Bertisch, H., & Rivara, F. P. (2018). Unmet Rehabilitation Needs After Hospitalization for Traumatic Brain Injury. *Pediatrics*, 141(5), e20172859. <https://doi.org/10.1542/peds.2017-2859>

Gerrard-Morris, A., Taylor, H. G., Yeates, K. O., Walz, N. C., Stancin, T., Minich, N., &

Wade, S. L. (2010). Cognitive development after traumatic brain injury in young children. *Journal of the International Neuropsychological Society*, 16(1), 157–168. <https://doi.org/10.1017/S1355617709991135>

Glang, A., Todis, B., Thomas, C., Hood, D., Bedell, G., & Cockrell, J. (2008). Return to school following childhood TBI: Who gets services? *NeuroRehabilitation*, 23, 477–486. <https://doi.org/10.3233/NRE-2008-23604>

Greene, N. H., Kernic, M. A., Vavilala, M. S., & Rivara, F. P. (2014). Variation in pediatric traumatic brain injury outcomes in the United States. *Archives of physical medicine and rehabilitation*, 95(6), 1148–1155. <https://doi.org/10.1016/j.apmr.2014.02.020>

Grubenhoff, J. A., Deakyne, S. J., Comstock, R. D., Kirkwood, M. W., & Bajaj, L. (2015). Outpatient follow-up and return to school after emergency department evaluation among children with persistent post-concussion symptoms. *Brain injury*, 29(10), 1186–1191. <https://doi.org/10.3109/02699052.2015.1035325>

Haarbauer-Krupa, J., Ciccia, A., Dodd, J., Ettel, D., Kurowski, B., Lumba-Brown, A., & Suskauer, S. (2017). Service Delivery in the Healthcare and Educational Systems for Children Following Traumatic Brain Injury: Gaps in Care. *The*

Journal of Head Trauma Rehabilitation, 32(6), 367–377.

<https://doi.org/10.1097/HTR.0000000000000287>

Haider, A. H., Efron, D. T., Haut, E. R., DiRusso, S. M., Sullivan, T., & Cornwell, E. E., 3rd (2007). Black children experience worse clinical and functional outcomes after traumatic brain injury: an analysis of the National Pediatric Trauma Registry. *The Journal of trauma*, 62(5), 1259–1263.

<https://doi.org/10.1097/TA.0b013e31803c760e>

Hawley, C. A. (2003). Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK.

Brain Injury, 17(2), 105–129. <https://doi.org/10.1080/0269905021000010131>

Howarth, R., Blackwell, L., & Ono, K. (2016). Acute and Long-Term Outcomes Following Pediatric Traumatic Brain Injury. *Journal of Pediatric Neuroradiology*, 05(01), 026–031. <https://doi.org/10.1055/s-0036-1584285>

Kingery, K. M., Narad, M. E., Taylor, H. G., Yeates, K. O., Stancin, T., & Wade, S. L. (2017). Do children who sustain traumatic brain injury in early childhood need and receive academic services 7 years post-injury? *Journal of Developmental and Behavioral Pediatrics*, 38(9), 728–735.

<https://doi.org/10.1097/DBP.0000000000000489>

Kochanek, P. M., Tasker, R. C., Carney, N., Totten, A. M., Adelson, P. D., Selden, N. R., Davis-O'Reilly, C., Hart, E. L., Bell, M. J., Bratton, S. L., Grant, G. A., Kisson, N., Reuter-Rice, K. E., Vavilala, M. S., & Wainwright, M. S. (2019). Guidelines for the Management of Pediatric Severe Traumatic Brain Injury, Third Edition: Update of the Brain Trauma Foundation Guidelines. *Pediatric Critical Care Medicine*, 20(3S), S1. <https://doi.org/10.1097/PCC.0000000000001735>

Kurowski, B. G., Taylor, H. G., Yeates, K. O., Walz, N. C., Stancin, T., & Wade, S. L. (2011). Caregiver ratings of long-term executive dysfunction and attention problems after early childhood traumatic brain injury: Family functioning is important. *PM & R: The Journal of Injury, Function, and Rehabilitation*, 3(9), 836–845. <https://doi.org/10.1016/j.pmrj.2011.05.016>

Kurowski, B. G., Wade, S. L., Kirkwood, M. W., Brown, T. M., Stancin, T., & Taylor, H. G. (2013). Behavioral Predictors of Outpatient Mental Health Service Utilization within 6 Months after Traumatic Brain Injury in Adolescents. *PM & R: The Journal of Injury, Function, and Rehabilitation*, 5(12), 10.1016/j.pmrj.2013.08.589. <https://doi.org/10.1016/j.pmrj.2013.08.589>

Lever, K., Peng, J., Lundine, J. P., Caupp, S., Wheeler, K. K., Sribnick, E. A., & Xiang,

H. (2019). Attending Follow-up Appointments After Pediatric Traumatic Brain Injury: Caregiver-Perceived Barriers and Facilitators. *Journal of Head Trauma Rehabilitation, 34*(2), E21-E34. <https://doi.org/10.1097/HTR.0000000000000433>

Levin, H. S., Hanten, G., Roberson, G., Li, X., Ewing-Cobbs, L., Dennis, M., Chapman, S., Max, J. E., Hunter, J., Schachar, R., Luerssen, T. G., & Swank, P. (2008). Prediction of cognitive sequelae based on abnormal computed tomography findings in children following mild traumatic brain injury. *Journal of Neurosurgery. Pediatrics, 1*(6), 461–470. <https://doi.org/10.3171/PED/2008/1/6/461>

Moore, M., Jimenez, N., Rowhani-Rahbar, A., Willis, M., Baron, K., Giordano, J., Crawley, D., Rivara, F. P., Jaffe, K. M., & Ebel, B. E. (2016). Availability of Outpatient Rehabilitation Services for Children After Traumatic Brain Injury: Differences by Language and Insurance Status. *American journal of physical medicine & rehabilitation, 95*(3), 204–213. <https://doi.org/10.1097/PHM.0000000000000362>

Narad, M. E., Minich, N., Taylor, H. G., Kirkwood, M. W., Brown, T. M., Stancin, T., & Wade, S. L. (2015). Effects of a web-based intervention on family functioning following pediatric traumatic brain injury. *Journal of Developmental and*

Behavioral Pediatrics, 36(9), 700-707.

<https://doi.org/10.1097/DBP.0000000000000208>

Rivara, F. P., Koepsell, T. D., Wang, J., Temkin, N., Dorsch, A., Vavilala, M. S., Durbin, D., & Jaffe, K. M. (2011). Disability 3, 12, and 24 months after traumatic brain injury among children and adolescents. *Pediatrics*, 128(5), e1129–e1138.

<https://doi.org/10.1542/peds.2011-0840>

Rivara, F. P., Ennis, S. K., Mangione-Smith, R., MacKenzie, E. J., Jaffe, K. M., & National Expert Panel for the Development of Pediatric Rehabilitation Quality Care Indicators (2012a). Quality of care indicators for the rehabilitation of children with traumatic brain injury. *Archives of physical medicine and rehabilitation*, 93(3), 381–385.e9. <https://doi.org/10.1016/j.apmr.2011.08.015>

Rivara, F. P., Koepsell, T. D., Wang, J., Temkin, N., Dorsch, A., Vavilala, M. S., Durbin, D., & Jaffe, K. M. (2012b). Incidence of Disability Among Children 12 Months After Traumatic Brain Injury. *American Journal of Public Health*, 102(11), 2074–2079. <https://doi.org/10.2105/AJPH.2012.300696>

Saatman, K. E., Duhaime, A. C., Bullock, R., Maas, A. I., Valadka, A., Manley, G. T., &

Workshop Scientific Team and Advisory Panel Members (2008). Classification of traumatic brain injury for targeted therapies. *Journal of Neurotrauma*, 25(7), 719–738. <https://doi.org/10.1089/neu.2008.0586>

Slomine, B. S., McCarthy, M. L., Ding, R., MacKenzie, E. J., Jaffe, K. M., Aitken, M. E., Durbin, D. R., Christensen, J. R., Dorsch, A. M., & Paidas, C. N. (2006). Health care utilization and needs after pediatric traumatic brain injury. *Pediatrics*, 117(4), e663–e674. <https://doi.org/10.1542/peds.2005-1892>

Spaw, A. J., Lundine, J. P., Johnson, S. A., Peng, J., Wheeler, K. K., Shi, J., Yang, G., Haley, K. J., Groner, J. I., & Xiang, H. (2018). Follow-up care adherence after hospital discharge in children with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 33(3), E1–E10. <https://doi.org/10.1097/HTR.0000000000000314>

Taylor, H. G., Swartwout, M., Yeates, K. O., Walz, N. C., Stancin, T., & Wade, S. L. (2008). Traumatic Brain Injury in Young Children: Post-Acute Effects on Cognitive and School Readiness Skills. *Journal of the International Neuropsychological Society: JINS*, 14(5), 734–745. <https://doi.org/10.1017/S1355617708081150>

Taylor, C.A., Bell, J.M., Breiding, M.J., Xu, L (2017). Traumatic Brain Injury–Related

Emergency Department Visits, Hospitalizations, and Deaths — United States, 2007 and 2013. *MMWR Surveillance Summaries*; 66 (No. SS-9):1–16.

DOI: <http://dx.doi.org/10.15585/mmwr.ss6609a1external icon>.

Teasdale, G., Jennett, B. (1974) Assessment of coma and impaired

consciousness. A practical scale. *Lancet*, 2(7872), 81-84.

[https://doi.org/10.1016/S0140-6736\(74\)91639-0](https://doi.org/10.1016/S0140-6736(74)91639-0)

Tonks, J., Slater, A., Frampton, I., Wall, S. E., Yates, P., & Williams, W. H. (2009). The development of emotion and empathy skills after childhood brain injury.

Developmental Medicine & Child Neurology, 51(1), 8–16.

<https://doi.org/10.1111/j.1469-8749.2008.03219.x>

Wade, S. L., Gerry Taylor, H., Yeates, K. O., Drotar, D., Stancin, T., Minich, N. M., & Schluchter, M. (2006). Long-term parental and family adaptation following pediatric brain injury. *Journal of pediatric psychology*, 31(10), 1072–1083.

<https://doi.org/10.1093/jpepsy/jsj077>

Wade, S. L., Cassedy, A., Walz, N. C., Taylor, H. G., Stancin, T., & Yeates, K. O.

(2011). The relationship of parental warm responsiveness and negativity to emerging behavior problems following traumatic brain injury in young children.

Developmental Psychology, 47(1), 119–133. <https://doi.org/10.1037/a0021028>

Wade, S. L., Karver, C. L., Taylor, H. G., Cassedy, A., Stancin, T., Kirkwood, M. W., & Brown, T. M. (2014). Counselor-assisted problem solving improves caregiver efficacy following adolescent brain injury. *Rehabilitation Psychology, 59*(1), 1–9. <https://doi.org/10.1037/a0034911>

Wade, S. L., Zhang, N., Yeates, K. O., Stancin, T., & Taylor, H. G. (2016). Social Environmental Moderators of Long-term Functional Outcomes of Early Childhood Brain Injury. *JAMA Pediatrics, 170* (4), 343–349. <https://doi.org/10.1001/jamapediatrics.2015.4485>

Wechsler, B., Kim, H., Gallagher, P. R., DiScala, C., & Stineman, M. G. (2005). Functional status after childhood traumatic brain injury. *The Journal of Trauma, 58*(5), 940–950. <https://doi.org/10.1097/01.ta.0000162630.78386.98>

Zonfrillo, M. R., Durbin, D. R., Koepsell, T. D., Wang, J., Temkin, N. R., Dorsch, A. M., Vavilala, M. S., Jaffe, K. M., & Rivara, F. P. (2014). Prevalence of and Risk Factors for Poor Functioning after Isolated Mild Traumatic Brain Injury in Children. *Journal of Neurotrauma, 31*(8), 722–727. <https://doi.org/10.1089/neu.2013.3088>

according to GCS	Sig. (2-tailed)	0.194	0.835								
Length of inpatient hospital stay	Correlation Coefficient	0.022	0.431	-0.452	--						
	Sig. (2-tailed)	0.929	0.066	0.052							
Mechanism of injury	Correlation Coefficient	-0.069	-0.025	-0.148	-0.221	--					
	Sig. (2-tailed)	0.778	0.918	0.546	0.364						
Estimate of years since injury	Correlation Coefficient	-0.625**	-0.357	-0.237	-0.172	0.229	--				
	Sig. (2-tailed)	0.004	0.133	0.328	0.481	0.347					
Age at interview	Correlation Coefficient	.701**	0.345	0.133	-0.124	0.311	-0.126	--			
	Sig. (2-tailed)	0.001	0.148	0.588	0.612	0.195	0.607				

Caregiver's level of education	Correlation Coefficient	0.159	0.004	-0.026	-0.084	0.211	0.037	0.155	--		
	Sig. (2-tailed)	0.515	0.986	0.915	0.733	0.386	0.879	0.526			
Annual household income	Correlation Coefficient	0.257	0.006	0.319	0.118	-0.194	-0.132	0.199	-0.113	--	
	Sig. (2-tailed)	0.288	0.980	0.183	0.631	0.427	0.589	0.414	0.644		
Caregiver's age at interview	Correlation Coefficient	.588*	0.443	0.141	0.178	-0.334	-.543*	0.305	0.181	-0.071	--
	Sig. (2-tailed)	0.013	0.075	0.589	0.495	0.190	0.024	0.233	0.488	0.786	
CASE report for design and layout of home	Correlation Coefficient	0.015	-0.143	-.478*	0.202	0.176	-0.102	0.183	-0.136	0.319	-0.050
	Sig. (2-tailed)	0.952	0.560	0.038	0.406	0.471	0.677	0.454	0.579	0.183	0.849

CASE report for assistive devices	Correlation	-0.055	0.132	0.082	0.230	-0.327	-0.220	-0.335	-0.424	0.084	-0.142
	Coefficient										
	Sig. (2- tailed)	0.823	0.589	0.739	0.343	0.172	0.366	0.161	0.070	0.734	0.586
CASE report for inadequate or lack of finances	Correlation	0.333	0.245	-0.020	-0.058	-0.206	-0.236	0.314	-.577**	-0.142	-0.018
	Coefficient										
	Sig. (2- tailed)	0.164	0.313	0.934	0.814	0.397	0.331	0.191	0.010	0.562	0.947
CASE report for family stress	Correlation	-0.433	0.000	-0.274	0.107	0.101	.458*	-0.208	-0.363	-0.118	-.520*
	Coefficient										
	Sig. (2- tailed)	0.064	1.000	0.257	0.662	0.682	0.049	0.394	0.126	0.630	0.032
CASE report for lack of or problems with	Correlation	0.178	0.162	-.478*	0.222	0.176	-0.126	0.279	-0.316	-0.143	0.126
	Coefficient										
	Sig. (2- tailed)	0.466	0.508	0.038	0.360	0.471	0.606	0.247	0.187	0.560	0.629

lack of support in community	Sig. (2-tailed)	0.174	0.974	0.043	0.370	0.242	0.230	0.663	0.620	0.135	0.111
CASE report for attitudes in community	Correlation Coefficient	-0.040	-0.106	-0.126	0.022	-0.136	0.233	-0.001	-0.123	-0.082	0.222
	Sig. (2-tailed)	0.872	0.665	0.607	0.927	0.579	0.338	0.997	0.615	0.740	0.392
CASE report for lack of services in community	Correlation Coefficient	-.463*	-0.129	-0.360	-0.061	0.309	0.439	-0.184	0.031	-.470*	-.492*
	Sig. (2-tailed)	0.046	0.598	0.130	0.805	0.198	0.060	0.452	0.901	0.042	0.045
CASE report for crime or violence in the community	Correlation Coefficient	-0.196	0.012	-.500*	0.387	0.088	0.334	0.128	-0.149	-0.093	0.154
	Sig. (2-tailed)	0.421	0.961	0.029	0.102	0.721	0.162	0.601	0.544	0.705	0.554

CASE report for design and layout of school or work	Correlation Coefficient	0.094	-0.003	-0.206	-0.156	0.148	0.251	.477*	-0.163	-0.105	-0.220
	Sig. (2- tailed)	0.701	0.991	0.398	0.523	0.546	0.300	0.039	0.504	0.669	0.396
CASE report for lack of support in school	Correlation Coefficient	-.463*	-0.129	-0.360	-0.061	0.309	0.439	-0.184	0.031	-.470*	-.492*
	Sig. (2- tailed)	0.046	0.598	0.130	0.805	0.198	0.060	0.452	0.901	0.042	0.045
CASE report for attitudes at school	Correlation Coefficient	-0.160	0.055	-0.027	-0.170	0.256	0.443	0.027	-0.422	-0.236	-0.244
	Sig. (2- tailed)	0.512	0.823	0.914	0.485	0.290	0.058	0.912	0.072	0.331	0.345
CASE report for	Correlation Coefficient	-0.153	-0.121	-0.012	-0.156	0.255	0.181	0.084	-0.277	0.113	-.673**

lack of assistance from people in school	Sig. (2-tailed)	0.533	0.621	0.961	0.523	0.292	0.460	0.733	0.252	0.644	0.003
CASE report for lack of school services	Correlation Coefficient	-0.394	-0.418	-0.011	-0.294	0.071	0.231	-0.249	-0.279	-0.120	-.758**
	Sig. (2-tailed)	0.095	0.075	0.964	0.222	0.772	0.341	0.304	0.248	0.624	0.000
CASE report for problems with government agencies	Correlation Coefficient	0.031	0.166	-.492*	0.224	0.176	0.114	0.129	-0.035	-0.319	0.157
	Sig. (2-tailed)	0.900	0.497	0.032	0.356	0.472	0.642	0.597	0.888	0.182	0.548
CASE report for	Correlation Coefficient	-0.238	-0.027	-.623**	0.119	0.148	0.225	-0.066	0.195	-0.299	-.539*

lack of information on diagnosis	Sig. (2- tailed)	0.327	0.912	0.004	0.629	0.545	0.355	0.789	0.423	0.213	0.026
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*Correlation is significant at the 0.05 level.

**Correlation is significant at the 0.01 level.