



Prevalence of post-traumatic stress disorder in caregivers of pediatric neurosurgical patients

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Abstract

Background Having a child receive a neurosurgical diagnosis creates significant stress and anxiety in caregivers. The stress of these life-threatening and emotionally charged diagnoses may put caregivers at risk for developing post-traumatic stress disorder (PTSD). While PTSD has been studied in a variety of caregivers of pediatric populations, to the best of our knowledge, it has yet to be examined in caregivers commonly seen in general pediatric neurosurgical practices. This study was designed to gain an understanding of the prevalence of PTSD within this population.

Methods A cross-sectional survey method was utilized. Participants completed both a survey to provide demographic information, and the Posttraumatic Stress Checklist for DSM-5 (PCL-5) which is used to make a provisional diagnosis of PTSD. Surveys were distributed both in person and online between December 2018 and April 2019.

Results One hundred sixty-eight surveys were included in the study. According to the DSM-5 diagnostic criteria, 44.6% ($n = 75$) of caregivers screened positively for a provisional diagnosis of PTSD. The specific neurosurgical diagnosis ($p = 0.002$), number of surgeries ($p = 0.008$), and category of the last surgery ($p = 0.026$) impacted the rate of PTSD symptoms in this population. Most caregivers who screened positive for PTSD experience a high level of disturbing memories and physical reactions to the events and avoid reminders of the medical experience. Caregivers also report a loss of interest in activities, feel distant from other people, and have difficulties with concentration and sleep. There was no significant relationship between caregivers who identified having a high level of anxiety before their child was diagnosed and who screened positive for PTSD.

Conclusion This study has identified a higher number of caregivers screening positive for PTSD within pediatric neurosurgical patients, than previously reported in other populations. Specific neurosurgical diagnosis, number of surgeries, and category of last surgery all impact a positive screen for the condition. Caregivers who avoid remembering events surrounding their child's diagnosis are at a higher risk of having the condition. The results highlight the need to identify ways to decrease the impact of a pediatric neurosurgical diagnosis on the mental health of caregivers. Future research focused on early mental health intervention for caregivers of pediatric neurosurgical patients may be helpful in reducing the long-term impact of this difficult condition.

Keywords PTSD · Neurosurgical caregivers · Pediatric patients

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Introduction

Primary caregivers of a child receiving a neurosurgical diagnosis can experience a high level of stress and anxiety as they struggle to adapt to a variety of urgent and life-altering conditions [1]. The long-term health outcomes and quality of life in this population can range from near-normal to major physical, cognitive, social, and emotional deficits [2]. Caregivers are frequently faced with accepting that their child may have limited return to pre-diagnosis academic or behavioral status and may even require assistance throughout their lifetime. This “new normal” can create a negative impact on the caregiver’s physical and mental health [3–6].

The stress of these potentially life-threatening and emotionally charged diagnoses place caregivers at risk for developing post-traumatic stress disorder (PTSD). PTSD is a psychiatric disorder that follows exposure to a traumatic event involving the threat of death or serious injury to the individual or family member. PTSD is diagnosed by identifying behaviors in four different clusters of symptoms which cause significant impairment in the individual’s social interactions, ability to work, and cannot be the result of a medical condition, medication, drugs, or alcohol. The four clusters of symptoms include (1) re-experiencing negative memories related to a traumatic event; (2) avoiding things that trigger memories, thoughts, feelings, or external reminders of the event; (3) negative cognitions and mood which includes persistent blame of self or others, estrangement, inability to remember key aspects of event, or diminished interest in activities; and (4) arousal which manifests as becoming aggressive, reckless, experiencing sleep disturbances, or being hypervigilant. Caregivers must experience at least one symptom of re-experiencing and avoidance and two symptoms of negative alterations in mood and changes in arousal or reactivity, for a minimum of a month following direct or indirect exposure to a traumatic event in order to be classified as having PTSD [7].

In Canada, the rate of PTSD among the general population is around 2.4%, with 9.2% of the population experiencing PTSD at some point in their lifetime [8]. In the USA, the annual rate of PTSD is slightly higher at 3.5%, but the lifetime rate is lower at 6.8% [9]. PTSD is known to be higher in groups of people that experience sustained high levels of stress. This is commonly the case for members of the military, especially those who have been deployed to active war zones. Over the course of their lifetime, about 11% of members of the Canadian military will have met the diagnostic criteria for PTSD [10], a rate similar to the US military, which is reported as being between 5 and 20% [11]. First responders, including police, firefighters, and paramedics, have also been studied for rates of PTSD due to their routine exposure to significant physical and psychological stressors. A large systematic review examining the rate of PTSD among rescue workers

found it to be similar to those in the military with a worldwide prevalence of approximately 10% [12].

Caregiver distress regarding the future of a child who had been diagnosed with an acute or chronic condition can elicit levels of anxiety and stress similar to those experienced by both members of the military and first responders and contribute to the likelihood of a caregiver developing PTSD. Among caregivers, gender, level of education, a history of depression, and age of the caregiver have all been reported as contributing to a higher level of PTSD [13]. The incidence of PTSD among caregivers of pediatric patients with a chronic illness or undergoing invasive procedures had been reported at 22.8 %, with a pooled prevalence rate of 4.2 when comparing with healthy counterparts [14]. Caregivers of pediatric patients undergoing open heart surgery had similar rates with 25% of fathers and 26% of mothers screening positive for PTSD [15]. Among caregivers of pediatric transplant patients, 27% met the DSM-5 diagnostic criteria of the condition [16]. In pediatric services where the length of time of the condition is often reduced, such as with general surgery or trauma, the rate of PTSD was much lower, around 10–12% [17, 18]. There have been few studies looking specifically at pediatric neurosurgery patients and caregivers. A recent study by Carmassi et al. [19] examined 199 caregivers of children who had been diagnosed with epilepsy and found that 15.7% of those caregivers met the criteria of having PTSD. A similar rate was found among caregivers of patients who underwent surgical treatment for hydrocephalus with 16.07% of caregivers scoring over 33 on the PCL-5 suggestive of a PTSD diagnosis [20].

The purpose of this study was to better understand (1) the prevalence of PTSD symptoms among caregivers of pediatric neurosurgical patients as measured by the PCL-5 and significant demographic characteristics associated with those who screen positive for PTSD and (2) to identify any PCL-5 questions associated with a positive screen for PTSD. To the best of our knowledge, there have been no publications examining the prevalence of PTSD in caregivers of pediatric patients in a general neurosurgical practice.

Methods

Participants

Convenience sampling was used to recruit participants both in person and online between December 2018 and April 2019. Inclusion criteria was as follows: primary caregiver of the pediatric neurosurgical patient, competent in understanding and reading English, neurosurgical patient between the ages of 0–18 years at time of diagnosis, seen at the selected children’s hospital, and had a neurosurgical diagnosis for longer than 1 month. Surveys were required to have the PCL-5 and demographic questions completed in order to be included.

One hundred eighteen studies were handed out in clinic, and 96 were returned for a response rate of 81%. In addition, 80 online surveys were completed. It is difficult to quantify the response rate for the online as the link to the survey was posted, but there is no way to know how many caregivers viewed the link but chose not to complete the survey. Of the 176 surveys returned, 8 were excluded as they did not meet the inclusion criteria, did not fully complete the PCL-5, or did not properly fill out the demographic questions, leaving 168 surveys included in the final analysis.

Measures

PTSD Checklist for DSM-5 (PCL-5)

The PCL-5 is a widely used and recognized, self-report measure that assesses the presence and severity of PTSD symptoms [21]. This tool is easily and readily accessible to the public in online and printable versions. The PCL-5 consists of 20 questions that follow the DSM-5 criteria for diagnosing PTSD. Domains represented on subscales include criterion B (re-experiencing), criterion C (avoidance), criterion D (negative thoughts or feelings), and criterion E (hyperarousal and reactivity). It is scored on a 5-point Likert scale where the caregiver reports their symptoms from 0 (not at all) to 4 (extremely). PCL-5 scores can range from 0 to 80 with a higher score indicating greater severity of PTSD symptoms [22]. The National Center for PTSD recommends making a provisional diagnosis by either setting a cut-off score and summing the 20 questions or treating each item rated 2 (moderate) or higher to track the DSM-5 system of diagnosing PTSD (at least 1 criteria B and 2 criteria C, D, and E items) [23]. For the purpose of this study, the DSM-5 categorization method was utilized to assess for a provisional diagnosis of PTSD (see Appendix 1).

Demographic information

Demographic information about the patient was collected by checking off relevant boxes whether online or in person. Information included in the demographic survey included basic demographic information, financial information, diagnosis-related questions, and generalized questions about a previous history of anxiety and other stressful events (see Appendix 2).

Procedure

Ethical and operational approvals were obtained from the University of Alberta Health Research Ethics Board (Pro000884403) and the Northern Alberta Clinical Trials and Research Center. In-person surveys were distributed by a research assistant both in clinic and the inpatient setting. To

ensure anonymity, study participants completed the questionnaire in a private environment, sealed it in an envelope, and placed it into a clearly labeled collection box located at both locations. Consent to participate in the study was implied once the questionnaire was completed and placed in the collection box. The online survey format was shared on social media platforms that were known to have a high number of pre-existing neurosurgical caregiver participants. Caregivers were asked to only submit one survey, either online or in person. There was no identifying information attached to the online surveys, and consent was implied once the questionnaire was submitted online.

Data analysis

All data were analyzed using SPSS version 27. Frequency tables and measures of central tendency were determined. Data was examined to identify the existence of any outliers within the subscales. Chi-square analysis was used to compare nominal variables, and ANOVAs were used for comparing continuous variables. Multiple linear regression analysis was used to explain the relationship between the demographic information collected and severity of PTSD symptoms in neurosurgical caregivers. Multiple linear regression was also used to determine which of the PCL-5 questions significantly predicted the presentation of PTSD symptoms for those who screened positively for PTSD. For all analyses, $p < 0.05$ was used to determine significance. The original data was directly entered into SPSS double-checked by the Principle Investigator, with a secondary person randomly checking 10% of the data entry to ensure accuracy of data input and no errors were found.

Results

Sample characteristics

Of the 168 surgeries completed, 72 (43%) of the surveys were completed online and 96 (57%) in clinic. Majority of the participants were mothers ($n = 150$; 82%), married or common law ($n = 144$; 82%), Caucasian ($n = 127$; 77%), between the ages of 31 to 40 ($n = 92$; 56%), and lived with their child full time ($n = 159$; 97%). Most caregivers included in the study had completed a post-secondary level of education ($n = 127$; 76%), with the remaining 37 ($n = 41$; 24%) having received a high school degree or less. Caregivers reported having what they identified as having enough household income to meet their financial needs 77% of the time ($n = 129$). Most caregivers had accessed support services when required ($n = 71$; 59%). Sixty-three percent of caregivers reported having no prior history of anxiety prior to their child's neurosurgical

diagnosis ($n = 106$) (see Table 1 for detailed caregiver demographic information).

Patient demographic information identified that approximately half of the patients were female ($n = 91$; 55.5%) and between the ages of 4–11 years ($n = 79$; 48.5%). Patients diagnosed with hydrocephalus made up the largest neurosurgical group

identified in the study ($n = 39$; 23%), followed by tumors ($n = 34$; 20%), craniosynostosis ($n = 27$; 16%), tethered cords ($n = 18$; 11%), Chiari malformations ($n = 17$; 10%), stroke/bleed ($n = 9$; 5%), trauma ($n = 6$; 4%), and epilepsy ($n = 5$; 3%). Conditions identified by caregivers as “Other” made up the remaining 7.5%. More than half of the patients had been diagnosed for more than 1 year ($n = 94$; 55.6%), and three quarters had three or less surgical procedures ($n = 123$; 72.8%). Table 2 contains patient demographic information.

Table 1 Caregiver demographic characteristics

Demographic characteristic	<i>N</i> (%)
Location survey filled out?	
Online	85 (53.9)
In person	76 (46.1)
Relationship to child?	
Mother	150 (82.3)
Father	18 (11)
Other	11 (6.7)
Lives with child?	
Full time	159 (97)
Shared custody	5 (3)
Other children in the home?	
Yes	133 (80.6)
No	32 (19.4)
Caregiver age?	
< 20	3 (1.8)
21–30	20 (12.1)
31–40	92 (55.8)
> 41	50 (30.3)
Marital status?	
Married/common law	144 (82.3)
Single/separated/divorced/widowed	28 (16)
Ethnicity?	
Caucasian/White	127 (77.4)
Black/African American	2 (1.2)
Asian	15 (9.1)
Aboriginal/Indigenous	10 (6.1)
Middle Eastern	3 (1.8)
Hispanic	2 (1.2)
Other	5 (3.0)
Level of education?	
Less than high school	7 (4.2)
High school degree	31 (18.8)
Post-secondary	127 (77)
Sufficient household income?	
Yes	129 (78.7)
No	35 (21.3)
Access to support services?	
Yes	71 (59.2)
No	49 (40.8)
Distance from hospital of residence?	
< 40 km	77 (45.6)
> 40 km	88 (52.1)
Prior history of anxiety?	
Yes	56 (34.6)
No	106 (65.4)

Predictors of PTSD symptomology in neurosurgical caregivers

When analyzing the results reported in the PCL-5 screening tool, we found that 44.6% ($n = 75/168$) of neurosurgical caregivers met the DSM-5 diagnostic criteria for a provisional diagnosis of

Table 2 Neurosurgical patient demographic characteristics

Demographic characteristic	<i>N</i> (%)
Patient's age	
0–3 years	58 (35.6)
4–7 years	42 (25.8)
8–11 years	37 (22.7)
12–18 years	26 (16)
Patient's sex	
Female	91 (55.5)
Male	73 (44.5)
Other	0 (0)
Diagnosis	
Bleeding/stroke	9 (5.6)
Brain/skull/spine tumor	32 (20)
Chiari malformation	16 (10)
Craniosynostosis	26 (16.3)
Epilepsy	5 (3.1)
Hydrocephalus	37 (23.1)
Tethered Cord	17 (10.6)
Trauma	6 (3.8)
Other	12 (7.5)
Time since diagnosis	
< 12 months	53 (31.4)
> 12 months	94 (55.6)
Number of surgeries	
0–3	123 (72.8)
> 3	41 (24.3)
Time since last surgery	
< 1 year	53 (31.6)
> 1 year	94 (63.9)
Category of last surgery	
Urgent	53.2 (35.6)
Elective	94 (64.4)

PTSD. Caregivers who screened positively for PTSD reported experiencing a high level of disturbing memories and strong physical reactions to the event, including feeling hyperalert, and avoiding reminders of the experience. Caregivers also reported a loss of interest in activities, feeling distant from other people, and difficulties with concentration and sleep.

Demographic characteristics were explored to identify any factors impacting caregivers who screened positively for PTSD symptoms. Caregivers of children who had greater than three surgeries had higher levels of PTSD symptomology ($X^2_{Yates}(1, n = 164) = 7.956, p = 0.003$). The neurosurgical diagnosis ($X^2(8, n = 167) = 21.62, p = 0.006$) and the category of the last surgery ($X^2(1, n = 147) = 4.96, p = 0.026$) also increased screening positively for PTSD (Table 3). Multiple linear regression analysis identified that the category of the last surgery predicted the presentation of PTSD symptomology in caregivers who screened positively with a beta of 0.208 ($p < 0.05$). No other demographic characteristics, including the time since surgery, the length of time since diagnosis, or a prior history of anxiety, were found to be statistically significant. There were no statistically significant differences between those who filled out the survey online and those who filled the survey out in person.

Using the PCL-5 to predict PTSD symptomology

Multiple linear regression analysis identified two PCL-5 questions that significantly predicted the presence of PTSD symptomology in caregivers. Over 93% of the participants

who screened positively for PTSD reported being “extremely” or “quite a bit” bothered by the PCL-5 items, “avoiding memories, thoughts, or feelings of the neurosurgical experience” ($\beta = 0.268, p = 0.002$) and “avoiding external reminders of the neurosurgical experience” ($\beta = 0.299, p = 0.001$).

Discussion

Having a child diagnosed with a neurosurgical condition is frequently the most stressful event a caregiver has faced in their lifetime. Understanding how this high level of stress may evolve into PTSD symptoms may offer some insight into the level of urgency for intervention and treatment for these caregivers, not only to safeguard their mental health but also to improve the home environment in which these vulnerable patients are living. Psychological factors such as adherence to maladaptive coping strategies, feelings of vulnerability and distress, and disorganized family functioning also negatively impact the physical and psychological well-being of caregivers, increasing their risk of developing PTSD [24]. When caregivers are unable to properly care for themselves emotionally, the patient is at risk for a prolonged and complicated recovery [13, 24–26]. The findings in this study confirm that neurosurgical caregivers experience PTSD symptomology at a rate as high as 44.6%, which is significantly higher than what is reported in other pediatric caregiver populations [13, 14, 17, 19, 25, 27–29]. The degree of PTSD symptomology in caregivers of pediatric neurosurgical patients is influenced by

Table 3 Demographic characteristic significantly related to screening positively for PTSD

Demographic characteristic	Positive screening for PTSD <i>N</i> (%)	Chi-square test for independence
Diagnosis		
Trauma (<i>n</i> = 6)	4 (66.7)	$X^2(8, n = 161) = 18.83$ $P = 0.016$ $\phi = 0.342$
Chiari malformation (<i>n</i> = 17)	6 (35.3)	
Brain/spine/skull tumor (<i>n</i> = 32)	17 (53.1)	
Hydrocephalus (<i>n</i> = 37)	20 (54.1)	
Craniosynostosis (<i>n</i> = 26)	5 (19.2)	
Epilepsy (<i>n</i> = 5)	4 (80)	
Tethered cord (<i>n</i> = 17)	4 (23.5)	
Bleed/stroke (<i>n</i> = 9)	6 (66.7)	
Other (<i>n</i> = 12)	4 (33.3)	
Number of surgeries		
0–3 (<i>n</i> = 123)	45 (36.6)	$X^2(1, n = 164) = 7.477$ $p = 0.006$ $\Phi = 0.214$
> 3 (<i>n</i> = 41)	25 (61.0)	
Category of last surgery		
Elective (<i>n</i> = 95)	37 (38.6)	$X^2(1, n = 146) = 4.51^a$ $P = 0.034$ $\Phi = 0.190$
Emergency (<i>n</i> = 51)	30 (58.8)	

the diagnosis, the number of surgeries, and the category of the previous surgery. Identifying these common factors that lead to a higher prevalence of PTSD allows clinicians to be able to identify at-risk caregivers in their practices. To our knowledge, this is the first study to identify these factors as significant predictive factors for PTSD symptomology in this population.

Caregivers who were identified as having a child with trauma, hydrocephalus, epilepsy, stroke/bleeding, and brain, spinal, or skull tumors experienced a higher prevalence of PTSD symptomology. Many of these specific diagnoses, with the possible exception of trauma, carry an ongoing risk of a relapse or requiring further surgery at some arbitrary point in the future. Caregivers often state that they constantly feel like they are “waiting for the other shoe to drop,” which can leave them in a prolonged state of anxiety and contribute to the symptoms that lead to a diagnosis of PTSD. This is correlated with the finding that caregivers who reported the last neurosurgical procedure to be urgent (requiring surgery within 48 h of new symptom onset) were also more likely to screen positively for PTSD. Providing caregivers with the necessary resources at diagnosis to develop coping skills that focus on living with the unknown may help to reduce the prevalence of PTSD in this population. Additionally, providing interactional teachings and information such as videos, virtual tours of the operating area, and preoperative visits with the nurse could reduce the stress associated with the unknown or misconceptions of possible future surgeries [30].

Identifying that caregivers who screened positively for PTSD symptoms tended to avoid memories, thoughts, or feelings of the neurosurgical experience and avoid external reminders of the neurosurgical experience could be useful for clinicians interacting with this vulnerable population. This finding could allow busy pediatric neurosurgical clinics a way to ask a few short questions to help identify caregivers at risk for the development of PTSD. Further research is needed to validate whether identifying a caregiver as “avoiding memories, thoughts, or feelings” and “avoiding external reminders” could be used as a quick screening tool to identify caregivers at risk for developing PTSD, in order to provide support where it is needed most.

Recommendations and implications

While it is impossible to eliminate all stress associated with a child being diagnosed with a neurosurgical condition, the findings in this study may identify areas in the care pathway where clinicians can lessen the impact on caregivers, ultimately reducing the prevalence of PTSD. Early mental health

interventions are essential to preventing the development of severe psychological distress and PTSD. Parents who experience severe acute stress disorder (ASD), with symptoms lasting from 2 days to 1 month following initial exposure to the trauma of witnessing their child undergo acute treatment tend to be at a significantly higher risk of developing PTSD [14]. Short-term interventions, such as cognitive behavioral therapy, are beneficial in reducing the negative impacts of stress on an individual’s level of functioning [31]. Providing proper resources early during hospitalization and maintaining long-term supports for vulnerable families following the exposure to stressful events can help decrease stress levels and prevent long-term mental health complications such as PTSD [26].

Further exploration aimed towards targeting the specific factors from an urgent intervention that causes increased stress may lead to a reduction in the amount and severity of PTSD symptoms within neurosurgical caregivers. Interventions such as online or printed resources in the emergency room clinics and inpatient units, specific training for health care professionals that will help identify at risk caregivers, and easily accessible mental health resources may be worth exploring in the future. As more knowledge is accumulated and more concepts are explored in this field of research, further education will have to be provided across the health care system to encourage early screening and interventions for these vulnerable pediatric neurosurgical caregivers.

Limitations

There are limitations to this study that are worth considering. We acknowledge the limitations of using a non-probability convenience sample as our findings may not represent the entire neurosurgical caregiver population. Caregivers of pediatric neurosurgical patients may have reduced response rates as a direct result of the overwhelming nature and exhaustion associated with their child’s illness. In addition, caregivers experiencing PTSD may have opted not to participate in the study as a direct result of the symptom of PTSD which causes caregivers to avoid reliving experiences surrounding their child’s illness; thus, this study may have underestimated the prevalence of PTSD in this particular caregiver population. Although the PCL-5 is a validated tool that is comparable to clinical PTSD screening tool, the preliminary diagnosis and screening of PTSD using a self-report measure is not as accurate as a face-to-face interview with a psychologist in a clinical setting. Despite the limitations to this study, the high prevalence of PTSD symptoms identified in caregivers of pediatric neurosurgical patients warrants further investigation.

Conclusion

The current study is the first study to specifically examine the prevalence of PTSD symptoms among caregivers within a general pediatric neurosurgical practice. There are many implications that can be drawn from this study including the need for more longitudinal studies examining the efficacy of interventions and the need for mental health resources for caregivers suffering from PTSD. Our findings show the importance of screening for PTSD symptoms in neurosurgical caregiver populations. Awareness towards the demographic characteristics that are significantly related to positively screening for PTSD allows health care practitioners to identify patients who may be at risk for PTSD symptomology. We recommend that future research be done to validate efficient screening tools that could be used in busy clinical setting and explore the benefits of providing mental health services at the time of diagnosis to decrease the significant number of caregivers experiencing PTSD in this population.

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Compliance with ethical standards

Ethical and operational approvals were obtained from the University of Alberta Health Research Ethics Board (Pro000884403) and the Northern Alberta Clinical Trials and Research Center.

Conflict of interest The authors declare that they have no conflict of interest.

Appendix 1

PTSD Checklist for DSM-5 (PCL-5)

PCL-5

Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
1.Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2.Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3.Suddenly feeling or acting as if the stressful experience was actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4.Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5.Having strong physical reactions when something reminded you of the stressful experience (e.g., heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6.Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7.Avoiding external reminders of the stressful experience (e.g., people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8.Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9.Having strong negative beliefs about yourself, other people, or the world (e.g., having thoughts such as I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10.Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4
11.Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12.Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13.Feeling distant or cut off from other people?	0	1	2	3	4
14.Trouble experiencing positive feelings (e.g., being unable to feel happiness or have loving feelings for people close to you)?	0	1	2	3	4
15.Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16.Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17.Being “super alert” or watchful or on guard?	0	1	2	3	4
18.Feeling jumpy or easily startled?	0	1	2	3	4
19.Having difficulty concentrating?	0	1	2	3	4
20.Trouble falling or staying asleep?	0	1	2	3	4

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Appendix 2. Demographic Information Survey Sheet

Demographic Information

1. Where you are filling out the survey:
 Clinic Inpatient ICU Online
2. Relationship to Child:
 Mother Father Grandparent Legal Guardian
3. Do you live with the child:
 Full-time Part-time
4. Are there other children in the household?
 Yes No
5. Your Age:
 < 20 21-30 31-40 > 41
6. Marital status:
 Married/ Common Law Single Divorced/ Separated Widowed
7. Ethnicity:
 Caucasian/ White Black/ African American Asian
 Aboriginal/ Indigenous Middle Eastern Hispanic
 Other
8. Level of education:
 Less than high school High School Degree Post-secondary
 Certificate Diploma Degree Advanced Degree
9. Is your household income sufficient for your family needs?
 Yes No
10. Do you access any of the following supports?
 Disability Tax Credit FSCD Alberta Works
 Other: _____
11. How far away do you live from the Stollery Children's Hospital?
 < 40 km 41-150 km > 151 km
12. Age of child:
 Years _____ Months _____
13. Sex of Child:
 Male Female Other
14. Diagnosis:
 Trauma Head shape Tethered Chord
 Chiari Malformation Epilepsy Brain infection
 Brain/ Skull Tumor Skull Lesion Bleeding/ Stroke
 Hydrocephalus Other: _____
15. Length of time since diagnosis:
 < 1 month 1- 6 months 7 - 11 months
 1- 2 years > 2 years
16. Other diagnosis or condition?
 No Yes
 If yes, please specify: _____
17. Number of surgeries: _____
18. Length of time since last surgery:
 < 1 month 1 - 6 months 7 - 11 months
 1 - 2 years > 2 years
19. Was the last surgery:
 Elective Emergency
20. Did you have a history of anxiety before your child's neurosurgical experience?
 Yes No
21. Are you experiencing any other stressful events outside of your child's neurosurgical treatment?
 Yes No

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