

Impact of COVID-19 on adolescent and emerging adult brain tumor survivors and their parents

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Abstract

Background: The COVID-19 pandemic has prompted unprecedented challenges, contributing to greater difficulties among families of children with special health care needs, such as pediatric brain tumor survivors. We examined the impact of the pandemic on psychosocial functioning of adolescent and emerging adult survivors and their parents. We hypothesized that COVID-19 disruptions and survivor social connectedness would be associated with survivor-reported posttraumatic stress and family outcomes, including family functioning, parenting, and parent mental health.

Procedure: Fifty-five families (44 survivors, 48 parents) were recruited via phone and email to participate in the study. Survivors were ages 13–25 ($M = 19.62$, $SD = 3.47$) and at least 5 years post diagnosis. Parents completed the COVID-19 Exposure and Family Impact Survey (CEFIS), and survivors completed the Environmental influences on Child Health Outcomes (ECHO) COVID-19 child self-report form, which assessed pandemic impacts on their psychosocial functioning.

Results: Parents reported a mean of 7.52 ($SD = 2.83$) disruptions to their families' lives. The pandemic negatively affected survivors' life satisfaction ($M_{diff} = 0.46$, $t(44) = 3.96$, $p < .001$), with 92% reporting reduced social connectedness ($n = 39$). Total disruptions due to COVID-19 and survivor social connectedness predicted survivor-reported post-traumatic stress, above and beyond survivors' pre-pandemic psychosocial risk. Most parents reported positive changes in their parenting ($n = 31$, 67.4%) and family cohesion ($n = 30$, 66.7%). However, they also reported worsened mood ($n = 28$, 62.3%) and increased anxiety ($n = 31$, 71.1%).

Conclusions: Parents and survivors reported positive and negative impacts of COVID-19, which had downstream consequences on survivor psychosocial functioning. Follow-up care should consider potential adverse effects on social connectedness and stress symptoms.

KEYWORDS

adolescent and emerging adult, COVID-19, pediatric brain tumor survivor, psychosocial functioning

1 | INTRODUCTION

The COVID-19 global pandemic and the resulting public and government response have introduced abrupt and unpredictable changes to families' daily lives. Stay-at-home orders and physical distancing measures were implemented in the United States beginning in March 2020. School closures were estimated to have impacted 55.1 million students across the United States.¹ This has placed an increased burden on parents to act as educators, with an estimated 30% of remote schooling involving parent instruction.²

A recent U.S. study found that family communication, relationship quality, and satisfaction decreased due to the pandemic.³ Studies have documented increases in child mental health symptoms and distress, even though children are less vulnerable to the virus itself. In Italy and Spain, parents reported increased screen time, less physical activity, and more sleep, and a majority reported changes in their children's behavior and emotional state.⁴ A Canadian study found that 70.2% of children and adolescents endorsed poorer functioning in at least one mental health domain compared to before the pandemic, and identified social isolation as a significant risk factor.⁵

Challenges associated with parenting during a pandemic have affected most families, but caregivers of youth with special health care and/or educational needs may experience additional burden. In Italy, parents of children with a mental or physical disorder reported higher levels of parental burnout and less perceived social support than parents of children without a disorder.⁶ Many of these parents reported increases in authoritarian parenting and verbal hostility. Another study found that 65% of parents of children with special education needs reported that the educational support their child received during distance learning was not sufficient.²

Based on existing evidence of the pandemic's impact, especially for families with pre-pandemic difficulties, we hypothesized that adolescent and emerging adult (AEA) survivors of pediatric brain tumor (BT) would be particularly vulnerable to COVID-19-related distress. Survivors of central nervous system tumors have lower self-reported life satisfaction and health-related quality of life,⁷ and are at increased risk for neurocognitive impairments across numerous domains, including executive functioning, processing speed, and academic achievement.⁸⁻¹¹ These impairments may decrease survivors' ability to participate and learn effectively in distance learning, where they may have fewer educational supports. Social and emotional impairment, including social withdrawal,¹² difficulties with friendships,¹³ emotional/affective dysfunction,¹² and depression⁸ are also prevalent. Risk factors include treatment variables (e.g., cranial irradiation),⁷ tumor size and location, low socioeconomic status (SES), and high stress.⁸ Some studies have identified female sex and younger age at diagnosis as risk factors, but results have been mixed.¹⁴⁻¹⁶ Protective factors include family social support, friend and peer connectedness,^{17,18} survivor self-esteem,¹³ and higher SES.^{13,19} Survivors' physical health status and personal relationships, both of which have been disrupted due to the pandemic, have a particularly significant impact on quality of life.²⁰

In addition to this population's already heightened risk for social isolation, social interaction has been reduced due to physical distancing guidelines. Preliminary estimates have found that 42.1% of childhood cancer survivors reported their mental health to be worse than before the pandemic; 81% scored above the clinical cutoff for anxiety, 59.6% for depression, and 21.1% for posttraumatic stress (PTS).²¹

We sought to add to the emerging literature on the impact of COVID-19 on children with medical or developmental concerns by examining the perceived impacts on AEA survivors of pediatric BT and their families. We sought to understand (1) the physical, financial, and social effects of the COVID-19 pandemic experienced by BT survivors and their families (hereafter referred to as "COVID-related disruptions"), and (2) the impact of COVID-related disruptions and survivor social connectedness on psychosocial functioning in BT survivors and their families. We hypothesized that survivors and their parents would report adverse effects of COVID-19 pandemic on their psychosocial functioning, with a dose-response relationship between COVID-19 disruptions and survivor and family psychosocial outcomes. Finally, in parallel with previous literature,²² we anticipated that survivor social connectedness would be associated with survivor outcomes, above and beyond pre-pandemic risk and COVID-related disruptions.

2 | METHOD

Parents and AEA survivors of BTs were recruited from a Midwestern academic medical center between June and October 2020 from a neuro-oncology survivor clinic. Participants were identified from a list of patients seen in the survivorship clinic during the previous year.

Parents and survivors were included if the survivor (1) had a history of a BT, (2) was at least 5 years postdiagnosis at the time of participation, and (3) was between the ages of 13 and 25. The 5-year time-point was chosen because the likelihood of recurrence is significantly lower and late effects have likely emerged by this point. Participants also needed to be able to read and comprehend the measures administered in English.

The Institutional Review Board (IRB) approved data collection. All participants were initially contacted by email or phone and provided with a written study information sheet and verbal explanation including potential risks and benefits. Parents and survivors 18 years of age and older consented, and adolescents ages 13-17 assented to participate in the study. Families completed surveys in REDCap.

2.1 | Measures

Parents completed a demographic form, and the survivor's tumor and treatment characteristics were abstracted from chart review to generate their Neurological Predictive Scale (NPS) score. The NPS is a measure used to quantify the cumulative effect of treatment- and tumor-related neurological risk factors.²³ It incorporates factors such as receipt of neurosurgery, type of radiation, receipt of chemotherapy,

use of seizure medication, and history of hydrocephaly. The total score ranges between 0 and 11. Prior research has demonstrated the reliability and validity of NPS in relation to neuropsychological and psychosocial functioning in survivors of pediatric BT.^{24–26}

2.1.1 | SES

We calculated a z-score that combined parental education and median census family income by address.²⁷

2.1.2 | ECHO COVID-19 child self-report form²⁸

BT survivors completed an abbreviated version of the Environmental influences on Child Health Outcomes (ECHO) COVID-19 child self-report form, which assessed the impact of the COVID-19 pandemic on the child specifically, including their ability to receive health care services and their social connectedness relative to before the pandemic (from “Much less socially connected” to “More socially connected”). The 20-item questionnaire measured how satisfied survivors were with their life from “Not at all” to “Very often” before and during the pandemic, as well as the perceived impact of COVID-19 on survivors’ life from “Extremely negative” to “Extremely positive.” The measure also screened for symptoms of posttraumatic stress symptoms (PTSS; e.g., avoiding reading or watching information about COVID-19, having distressing dreams about COVID-19), with nine symptoms rated on a 5-point Likert scale from “Not at all” to “Very often.” This measure was developed by the National Institutes of Health ECHO COVID-19 Task Force to assess the impact of living during the COVID-19 outbreak on adolescents ages 13–21. It includes original items as well as modified items from existing questionnaires, such as the Acute Stress Disorder Scale.²⁹ No psychometric properties are currently available.

2.1.3 | COVID-19 Exposure and Family Impact Survey³⁰

Parents completed the COVID-19 Exposure and Family Impact Survey (CEFIS), which measured disruptions in families’ lives due to the COVID-19 pandemic via 25 yes/no questions (e.g., our children’s education was disrupted, we had difficulty getting food, we self-quarantined). The questionnaire also assessed the impact of COVID-19 on family functioning, the caregiver’s ability to parent, and the parent’s mental health, using a 4-point Likert scale from “Made it a lot better” to “Made it a lot worse.” Two questions assessed the parent’s and child’s overall distress related to COVID-19 on a scale from 1 to 10, with one being “No distress” and 10 being “Extreme distress.” The CEFIS was developed in March and April 2020 using a rapid iterative process. Initial validation data indicated excellent internal consistency and supported its use for measuring exposure to COVID-19-related

events and the impact of these events on families in pediatric health care settings.³¹

2.2 | Data analysis

Responses on the CEFIS and ECHO were characterized using percentages and frequencies. Paired sample *t*-tests examined differences in survivor-reported life satisfaction before and during the COVID-19 pandemic. We also examined bivariate Pearson correlations among variables reported on the CEFIS and ECHO. Independent sample *t*-tests examined if results from the CEFIS differed between parents who lived with the survivor and those who did not. Because results did not differ, we report results from all caregivers who participated in the study. The number of disruptions were summed to create a “total COVID-19-related disruptions” variable. Responses from the ECHO PTSS screening questions were summed and averaged. Questions on the CEFIS regarding family functioning, parenting, and mental health were summed and averaged to create a “COVID’s impact on family functioning” variable.

A hierarchical regression was used to examine the contributions of disruptions due to COVID-19 and survivor social connectedness on survivor-reported PTSS related to COVID-19. Based on previous literature consistently documenting treatment factors and SES as predictors of psychosocial outcomes in pediatric BT survivors, we statistically controlled for their influences by entering SES and the NPS score in the first step. We entered the total number of disruptions due to COVID-19 in the second step and survivor-reported social connectedness in the third step. We also used a hierarchical regression to examine the impact of disruptions due to COVID-19 on family outcomes (i.e., the variable combining the impact of COVID on parenting, family functioning, and parental mental and physical health). We again controlled for the effects of SES and NPS in the first step, and then entered the total number of disruptions due to COVID-19 in the second step. We examined this regression both with and without caregivers who were not living with the survivor. Because the results did not differ, we report results from the analysis including all caregivers.

3 | RESULTS

We attempted to contact 122 survivors and parents; 55 families (45.1%) agreed to participate in the study, with 44 survivors and 48 parents completing questionnaires. Chi square and independent sample *t*-tests indicated that participants did not differ from those who did not participate on sex, race/ethnicity, age, age at diagnosis, or years since last treatment.

The sample of survivors was 55% male, 84.2% White, and on average 19.62 years old (*SD* = 3.47) at the time of participation (see Table 1). Parents were mostly mothers (*n* = 43, 89.6%) and 45.8% had at least a bachelor’s degree (see Table 2).

TABLE 1 Demographic characteristics of survivors (N = 55 families)

| Characteristic | Survivors (N = 55) |
|---|--------------------------|
| Male, <i>n</i> (%) | 30 (55%) |
| Race, <i>n</i> (%) | |
| White | 48 (84.2%) |
| African American | 3 (5.5%) |
| Native American/Alaskan/Hawaiian | 1 (1.8%) |
| Asian American | 3 (5.5%) |
| Ethnicity, <i>n</i> (%) | |
| Hispanic | 5 (8.8%) |
| Not Hispanic | 48 (84.2%) |
| No response | 2 (3.5%) |
| Geographic region, <i>n</i> (%) | |
| Appalachian | 12 (21.1%) |
| Rural | 8 (14%) |
| Rural and Appalachian | 3 (5.7%) |
| Age of survivor, years, <i>M</i> (<i>SD</i>) | 19.62 (3.47) |
| Teen (ages 13–17), <i>n</i> (%) | 20 (36.4%) |
| Emerging adult (ages 18–25), <i>n</i> (%) | 35 (63.6%) |
| Currently in school (high school/college) ^a , <i>n</i> (%) | 35 (79.5%) |
| Time since diagnosis, years, <i>M</i> (<i>SD</i>), range | 12.37 (4.24), 5.58–21.68 |
| Time since last treatment, years, <i>M</i> (<i>SD</i>), range | 10.62 (3.77), 4.19–20.67 |
| Diagnosis category, <i>n</i> (%) | |
| Astrocytoma/glioma | 33 (60%) |
| Medulloblastoma | 9 (16.4%) |
| Germ cell tumor | 3 (5.5%) |
| Ependymoma | 2 (3.6%) |
| Atypical teratoid-rhabdoid tumor | 2 (3.6%) |
| Others ^b | 6 (10.9%) |
| History of neurosurgery, <i>n</i> (%) | 50 (90.9%) |
| History of radiation, <i>n</i> (%) | 27 (47.3%) |
| History of chemotherapy, <i>n</i> (%) | 30 (54.5%) |
| Neurological Predictive Scale Score, <i>M</i> (<i>SD</i>) | 4.62 (2.30) |

^aBased off total number of survivors who completed a demographic form (*n* = 44).

^bOther tumor types included: craniopharyngioma, choroid plexus carcinoma, cerebellar peduncle lesion.

3.1 | Impact of COVID-19 pandemic on survivors

3.1.1 | Life satisfaction and impact

One-quarter (26.2%, *n* = 11) of AEA survivors indicated they were “rarely” or “sometimes” satisfied with their life prior to the pandemic, while 45.4% (*n* = 20) of AEA survivors indicated they were “rarely” or “sometimes” satisfied with their life during the COVID-19 pandemic (Figure 1). In a paired samples *t*-test, survivors reported greater satisfaction with life before compared to after the COVID-19 pandemic, $M_{diff} = 0.46$, $t(44) = 3.96$, $p < .001$.

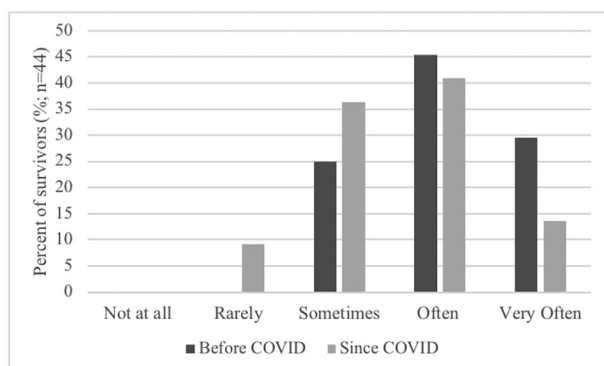
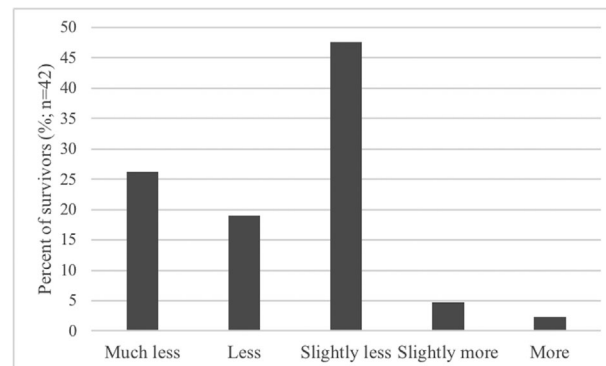
Most AEA survivors (75%, *n* = 33) indicated the COVID-19 pandemic had a “somewhat” to “extremely negative” impact on their life.

3.1.2 | Social connection

Compared to before COVID-19, many AEA survivors indicated (45.2%, *n* = 19) they felt “less” to “much less” socially connected, 47.6% (*n* = 20) felt “slightly less” socially connected, and 7.2% (*n* = 3) felt “more” to “slightly more” socially connected (Figure 2).

TABLE 2 Demographic characteristics of parents of pediatric brain tumor survivors

| Characteristic | Parents (N = 48) |
|---------------------------------|------------------|
| Relationship, n (%) | |
| Mother | 43 (89.6) |
| Father | 3 (6.3) |
| Grandfather | 1 (2.1) |
| Legal guardian (sibling) | 1 (2.1) |
| Current living situation, n (%) | |
| Living with survivor | 38 (84.4) |
| Total household income, n (%) | |
| \$49,999 or less | 9 (19.1) |
| \$50,000 to \$79,999 | 10 (21.3) |
| \$80,000 to \$120,000+ | 10 (21.3) |
| Don't know/prefer not to say | 18 (38.3) |
| Education, n (%) | |
| No high school diploma/GED | 0 (0) |
| High school diploma/GED | 15 (31.3) |
| At least 2 years college | 11 (19.3) |
| Bachelor's degree | 10 (20.8) |
| Graduate degree | 12 (25.0) |

**FIGURE 1** Survivor life satisfaction ratings before and since the COVID-19 pandemic. Survivors were asked how often they were satisfied with their life from “Not at all” to “Very often,” both pre-COVID-19 (retrospectively) and since COVID-19**FIGURE 2** Survivor ratings of social connectedness compared to before the COVID-19 pandemic

19 (20.4%, $n = 9$). Few AEA survivors had distressing dreams about COVID-19 (6.8%, $n = 3$).

3.1.3 | Posttraumatic stress symptoms

Some survivors indicated they “sometimes” to “often” tried to avoid reading or watching information about COVID-19 (47.7%, $n = 21$), felt a sense of time slowing down (40.9%, $n = 18$), tried to avoid thoughts or feelings about COVID-19 (36.3%, $n = 16$), had difficulty sleeping (40.9%, $n = 18$), felt in a daze (34.1%, $n = 15$), had temper outbursts (27.3%, $n = 12$), were startled easily (22.7%, $n = 10$), and were distressed when seeing something that reminds them of COVID-

3.2 | Impact of COVID-19 on family

Parents reported a mean of 7.52 (SD = 2.83) disruptions to their lives. Most commonly reported disruptions include a “stay-at-home” order (93.8%, $n = 45$), closure of schools/childcare centers (89.6%, $n = 43$), disruption to child(ren)’s education (75%, $n = 36$), and an inability to visit or care for a family member (68.8%, $n = 33$). See Table S1 for frequencies and percentages of COVID-19-related disruptions.

TABLE 3 Correlations between family and survivor outcomes

| | Family impact ^a | Parent distress ^b | AEA distress ^b | COVID-19 impact – survivor ^c | Survivor satisfaction with life during COVID-19 | PTS ^d symptoms |
|---|----------------------------|------------------------------|---------------------------|---|---|---------------------------|
| Family impact | – | .66*** | .54** | –.24 | –.31 | .36* |
| Parent distress | | – | .81*** | –.092 | –.31 | .18 |
| AEA distress | | | – | –.24 | –.51** | .30* |
| COVID-19 impact – survivor | | | | – | .52*** | –.52*** |
| Survivor satisfaction with life during COVID-19 | | | | | – | –.48** |
| PTS symptoms | | | | | | – |

^aImpact of COVID-19 on the family, including parental mental health, family functioning, and parenting.

^bParent-rated on a scale from 1–10.

^cPerceived impact of COVID-19 on survivor's life from "Extremely negative" to "Extremely positive."

^dPosttraumatic stress.

* $p < .05$. ** $p < .01$. *** $p < .001$.

3.3 | Impact of COVID-19 on family outcomes

When examining the seven items that comprised the family impact score, most parents ($n = 31$, 67.4%) indicated that the COVID-19 pandemic made their parenting "a little" or "a lot" better, improved how well family members got along ($n = 30$, 62.5%), and improved their ability to care for the survivor ($n = 26$, 65%). Over half of parents indicated that the COVID-19 pandemic negatively affected their physical well-being in the following areas: sleep ($n = 24$, 53.4%), eating ($n = 23$, 52.3%), and exercise ($n = 24$, 53.4%). Parents also reported the pandemic negatively affected their mood ($n = 28$, 62.3%) and increased their anxiety ($n = 31$, 71.1%). Parents also rated their overall distress due to COVID-19 on a scale from 1 to 10. Less than half ($n = 19$, 42.2%) rated their own distress as greater than a 5, with 11 (26.7%) parents rating their distress between an 8 and 10. Less than half ($n = 20$, 44.4%) of parents rated their survivor's distress as greater than a 5, with eight (18.8%) rating their children's distress between an 8 and 10. Parent ratings of their own distress and their child's distress were highly correlated, $r(45) = .81$, $p < .001$ (see Table 3).

3.4 | Predictors of survivor PTSS and family outcomes

In the hierarchical regression, the total number of disruptions due to COVID-19 predicted survivor-reported PTSS, above and beyond psychosocial risk. Disruptions due to COVID-19 explained 15% of the variance in the model. Survivor-reported social connectedness explained 23% of the variance above and beyond psychosocial risk and disruptions due to COVID-19 (see Table 4). Total number of disruptions due to COVID-19 did not predict COVID-19's impact on the family, above and beyond psychosocial risk. Table 3 examines correlations between family and survivor psychosocial functioning.

TABLE 4 Hierarchical regression examining the impact COVID-19-related disruptions on survivor and family outcomes and survivor social connectedness on survivor outcomes

| PTSS | B | t | R ² Δ |
|-----------------------------------|--------|----------|------------------|
| Step 1: | | | |
| Psychosocial risk ^a | –0.145 | –0.612 | .001 |
| | | | .211 |
| Step 2: | | | |
| Psychosocial risk | 0.059 | 0.056 | |
| Total disruptions due to COVID-19 | 0.454 | 2.64* | |
| | | | .231 |
| Step 3: | | | |
| Psychosocial risk | –0.031 | –0.034 | |
| Total disruptions due to COVID-19 | 0.949 | 2.536* | |
| Social connections ^b | –0.485 | –3.373** | |
| Family impact | | | |
| | | | .040 |
| Step 1 | | | |
| Psychosocial risk | 0.910 | 0.968 | |
| | | | .051 |
| Step 2 | | | |
| Psychosocial risk | 1.24 | 1.28 | |
| Total disruptions due to COVID-19 | 0.501 | 1.263 | |

^aPsychosocial risk combines SES and Neurological Predictive Scale.

^bQuestion related to perceptions of social connectedness during the pandemic as compared to pre-pandemic.

* $p < .05$. ** $p < .01$.

4 | DISCUSSION

Our data suggest that survivors were adversely affected by disruptions from the COVID-19 pandemic, which exerted downstream consequences on their psychosocial functioning. Survivors reported decreased life satisfaction and social connectedness and COVID-related PTSS, including avoiding thoughts and feelings about COVID-19. The number of disruptions due to COVID-19 and survivor social connectedness predicted PTSS, suggesting that the pandemic may affect survivors both through the concomitant disruptions to daily activities and alterations to friendships and social relationships. The effects of the pandemic on young survivors parallel those on other AEA but may take on added import given lower baseline levels of social participation. Surprisingly, most parents reported a positive impact on their parenting and family cohesion, although they also noted negative effects on their physical well-being and mental health.

The most commonly reported disruptions due to COVID-19 were receiving a “stay-at-home” order, school/childcare closures, and disruptions to education. School closures and transitions to remote schooling may have been particularly challenging for BT survivors, due to cognitive late effects associated with their cancer and its treatment.^{32–35} Often, survivors of BT have Individualized Education or 504 plans to support their learning.³⁶ However, survivors and parents frequently describe gaps in their understanding of their rights to special accommodations and academic supports, particularly in transitioning to college.³⁷ This uncertainty may be exacerbated in the context of COVID-19. Emerging literature in adolescents with ADHD suggests not all school accommodations (e.g., tutors, counseling) were provided during the transition to remote learning.³⁸ Additionally, many children receiving school-based services described remote learning as challenging, and parents of children with ADHD had less confidence managing remote learning than parents of children without ADHD.³⁸ Future research could explore parents’ confidence and ways they can support survivors’ remote learning.

Most survivors indicated that the COVID-19 pandemic negatively impacted their life. Survivors also endorsed PTSS related to the pandemic, which was correlated with their overall satisfaction with life, and the perceived impact of COVID-19 on survivors. Survivors of childhood cancer are more likely to experience traumatic stress due to the diagnosis and treatment of their cancer,³⁹ which may place them at higher risk for developing PTSS in the context of COVID-19. For example, it is possible that public health recommendations to quarantine, wash hands, wear masks, and stay vigilant about symptoms of illness may act as reminders of past treatments or hospitalizations.²¹ Future studies could examine survivor-reported PTSS in comparison to a healthy control group.

Interestingly, neither treatment factors nor SES predicted COVID-specific PTSS, despite these factors predicting psychosocial outcomes in previous research. Thus, it appears that more proximal factors (e.g., current level of social connectedness, disruptions to their lives) may be more salient with respect to survivors’ PTSS. The number of disruptions due to COVID-19 was related to survivor-reported PTSS,

and survivor-reported social connectedness was associated with PTSS above and beyond COVID-19-related disruptions. Overall, our findings parallel emerging literature^{5,40} and underscore the importance of social connectedness to survivor and family well-being. Strong peer relationships and maintenance of social connections may buffer against distress and anxiety related to COVID-19, with recent findings suggesting virtual time spent with friends decreases loneliness.⁴¹ However, it is likely that the quality of virtual social interactions (e.g., texting vs. video chats, individual conversations vs. group conversations) may be related to AEA’s psychological distress. Moreover, pre-existing negative group dynamics may lead to feelings of isolation and co-rumination in online interactions.⁴¹

Perhaps more important to AEA’s social connectedness is quality time spent with parents and other individuals at home. In fact, a recent study found that depression and anxiety were greater among adolescents who were home alone during the day.⁴² Parents can support their survivor through warm and consistent parent–child interactions. For AEA living outside the home, it will be important to monitor the quality of their virtual social time to decrease the likelihood of co-rumination and negative social interactions.^{41,42}

In addition to increasing survivors’ social connectedness, it is important to monitor their psychological distress, as mental health interventions may be warranted. Due to the decrease in health care utilization during the pandemic,⁴³ pediatricians and survivorship care clinics could consider administering a brief distress screening measure to be completed online or over-the-phone periodically, using a validated measure such as the Brief Symptom Inventory-18⁴⁴ or the Kessler Psychological Distress Scale.⁴⁵ Survivorship care clinics could also provide information to AEA survivors and their caregivers on ways to self-monitor their mental health (e.g., through diaries, phone applications).

Unfortunately, over half of parents reported that the pandemic had a detrimental impact on their physical and emotional well-being, and around one-quarter rated their overall distress due to COVID-19 as high. Previous research has demonstrated a significant association between parental mental health and parenting practices.^{46–48} Recent articles documented increases in parenting stress and associations between parenting stress, less structured parenting, and child psychopathology in the context of COVID-19.^{49–51} Despite this, most parents in our study reported improvements in their ability to parent their AEA survivor and other children, with about one-quarter of parents noting the pandemic negatively affected their parenting abilities. Interestingly, the number of disruptions due to COVID-19 were not associated with the pandemic’s impact on the family (i.e., the impact of COVID on parenting, parental mental and physical health, and family functioning). Parents may have adjusted their expectations and ratings of family functioning due to the drastic changes in family life related to the pandemic.³ Additionally, the CEFIS did not assess all the potential impacts of COVID-19 (e.g., not seeing close friends as often) or the length of disruptions.

Several limitations of the current study should be noted. Our sample size is small and limited by homogeneity in terms of race and ethnicity. We were unable to compare our sample to a healthy control

group. Therefore, we cannot say with certainty that AEA BT survivors and their parents experience the pandemic differently than other populations. It is also important to note that our data were collected over 5 months over the summer and fall of 2020, and participant data were collected across four different states, during which time COVID-19 infection rates and statewide infection control measures varied. Some data were collected during the summer months, and COVID-19's psychosocial impact on survivors and families may have differed when compared to during the school year. We did not assess survivor and family functioning before the COVID-19 pandemic. Instead, questions on the CEFIS and ECHO asked participants to compare their current experiences to their functioning before the pandemic. Therefore, our study is limited by recall bias. Additionally, we did not capture parents' and survivors' fear of contracting the virus, which may impact their outcomes.⁵² The ECHO was developed using a rapid iterative process, and psychometric properties have not yet been tested. Finally, our study was cross-sectional and does not inform our understanding of the effects of COVID-19 over time.

Despite these limitations, our study described the impact of COVID-19 pandemic on AEA survivors of childhood cancer and their parents, particularly highlighting the significance of life disruptions and social isolation. It will be important to continue to understand the impact of the pandemic on parental stress and parenting practices, especially as quality time with parents may buffer against survivor-reported loneliness and distress. Finally, our study underscored the need to assess survivors' psychosocial outcomes and capitalize on protective factors such as social connectedness. Referrals for psychosocial interventions may be warranted for some AEA survivors and their families who demonstrate clinically meaningful symptoms.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

Data are available on request from the authors.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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