

Parent perceptions of pediatric oncology care during the COVID-19 pandemic: An Australian study

Maria C. McCarthy^{1,2,3}  | Jessica Beamish^{1,2} | Catherine M. Bauld^{3,4} |
India R. Marks¹ | Tria Williams⁵ | Craig A. Olsson^{3,4,6} | Cinzia R. De Luca^{1,2} 

¹ Clinical Sciences, Murdoch Children's Research Institute, Melbourne, Victoria, Australia

² Children's Cancer Centre, Royal Children's Hospital, Parkville, Victoria, Australia

³ Department of Pediatrics, University of Melbourne, Melbourne, Victoria, Australia

⁴ Population Health, Murdoch Children's Research Institute, Melbourne, Victoria, Australia

⁵ Infection & Immunity, Murdoch Children's Research Institute, Melbourne, Victoria, Australia

⁶ Centre for Social and Early Emotional Development, School of Psychology, Faculty of Health, Deakin University, Burwood, Victoria, Australia

Correspondence

Maria McCarthy, Clinical Sciences, Murdoch Children's Research Institute, 48 Flemington Rd, Melbourne, VIC, Australia.
Email: maria.mccarthy@rch.org.au

Abstract

Background: We examined parents' perceptions of their child's oncology care during a period of significant COVID-19 restrictions in Australia.

Methods: Parents of children, 0–18 years, receiving hospital-based cancer treatment, completed a survey examining their COVID-19 exposure and impact, information and knowledge, and perception of their child's medical care. Recruitment occurred between October and November 2020.

Results: Eighty-four parents (95% mothers) completed the survey. Sixty-seven percent of patients were diagnosed pre-COVID-19. The majority of parents (76%) reported negative impacts of COVID-19 on family life, including parenting and emotional well-being despite exposure to COVID-19 cases being very low (4%). Family functioning and parent birthplace were associated with COVID-19 impact and distress. Parents perceived the hospital as a safe place during the pandemic. Very few parents reported delaying presentation to the emergency department (12%). The majority identified no change (69%) or delay (71%) in their child's treatment delivery. Over 90% of parents were confident that COVID-19 did not impact medical decision-making. They felt confident in their COVID-19 knowledge and sought information from trusted sources. Parents reported a positive relationship with their child's care team (93%); however, access to some support services was reduced.

Conclusion: Understanding patient and family experiences of pediatric oncology care across international contexts during the pandemic is important to inform present and future health care responses. In the Australian context of low infection rates and strict community restrictions, parents perceived their child's oncology care to be relatively unaffected. However, findings indicate that family well-being was impacted, which warrants further investigation.

KEYWORDS

childhood cancer, COVID-19, oncology, pandemic, parents, pediatric

1 | INTRODUCTION

The onset of the SARS-CoV-2 (coronavirus disease 2019 [COVID-19]) pandemic in early 2020 has presented significant challenges to pediatric oncology care worldwide. At the beginning of the pandemic, the impact of the virus on children undergoing cancer treatment was largely unknown.¹ Specific concerns included (i) whether young patients would be more susceptible to the virus due to their compromised immune states²; (ii) the extent to which oncology services would be suboptimal due to overwhelmed health care systems or reduction of patient-facing services³; and (iii) the psychological impact on youth and their families who were already enduring significant stress associated with cancer diagnosis and treatment.⁴

Australia is one of a handful of countries that have largely been able to maintain control of the virus, aided by geography, strict domestic and international travel restrictions, high levels of COVID-19 testing and contact tracing, and stringent “stay at home” orders. Within Australia, Victoria was the most affected state at the time. In March 2020, a State of Emergency was declared, and between March and October 2020, Melbourne experienced a total of 23 weeks of lockdown. During Victoria’s second lockdown, the strictest restrictions were in place for 8 weeks, from August 2 to September 28, 2020. During this time, residents were permitted to leave their homes for 1 hour a day and for one of four reasons: exercise, essential shopping, caregiving, and essential work. No public gatherings were allowed, face masks were mandatory, and individuals could not travel more than 5 km (3.1 miles) from their home. All non-essential services were closed, and residents were unable to leave their homes between 8 p.m. and 5 a.m. without a permitted reason. At the height of the pandemic, the highest number of cases in a day was 725 (August 6, 2020), and the highest weekly average was 491 cases per day (July 31 to August 7, 2020).

In line with these restrictions and with the global World Health Organization and the European Centre for Disease Prevention and Control guidelines, the Children’s Cancer Centre at the Royal Children’s Hospital (RCH) Melbourne made significant changes to patient care. Outpatient medical appointments were transitioned to telehealth where possible; staff rotated working from home; some allied health services were delivered online; hospital visitors were limited to one caregiver; all volunteer services ceased; personal protective equipment (PPE) was mandated for staff (surgical grade face masks and eye protection during patient interactions) and asymptomatic COVID-19 nasopharyngeal swabs were mandatory for patients before every emergency and elective procedure (between July 20 and November 24, 2020) with strict patient (and parent) isolation required while awaiting results.

The aim of this study was to understand the impact of the COVID-19 pandemic and any associated changes on the health and well-being of children and families receiving hospital-based oncology care at the RCH. The current paper reports on parent-reported COVID-19 exposure and impact, their knowledge and information seeking, and their perceptions of their child’s oncology care. A secondary aim was to

examine whether demographic, medical, or family characteristics were associated with COVID-19 impact and distress.

2 | METHODS

2.1 | Design

This cross-sectional study utilized an online survey comprising COVID-19-specific study variables, validated psychosocial measures and open-ended questions.

2.2 | Participants

Participants were parents of children aged 0–18 years who were undergoing active oncology treatment at the RCH Children’s Cancer Centre, Melbourne, Victoria. Active treatment was defined as children “admitted” to the hospital as an outpatient or inpatient for cancer-directed care during the COVID-19 period. Exclusion criteria included families where (i) the child had completed treatment prior to March/April 2020; (ii) parents had insufficient English to complete the survey; (iii) the child was receiving end-of-life treatment; and (iv) the family were identified by the clinical team as unsuitable to approach.

2.3 | Procedure

Eligible children were identified through the RCH electronic medical records (EMR) database. Recruitment was undertaken between October and November 2020. Eligible families received an information letter via clinical staff. Parents were then contacted by the research team 7–12 days after receiving the letter to obtain consent. The survey was distributed to consenting parents via data collection tool REDCap.⁵ Reminder emails were sent 1 week later if needed (maximum of three emails sent).

2.4 | Measures

2.4.1 | COVID-19 Exposure and Family Impact Survey (CEFIS)

The CEFIS⁶ questionnaire measures exposure and impact of the COVID-19 pandemic upon families of children with a pediatric health condition. The questionnaire has three sections. Part 1: 25 items (yes/no responses) that measure “exposure” to COVID-19 and related events. Scores are calculated as the sum of the 25 items (range 0–25); higher scores indicate more exposure. Part 2: 12 items (10 items on a four-point Likert scale [*Made it a lot better, made it a little better, made it a little worse, made it a lot worse, or a not applicable* option], and two items on a 10-point scale) that measure “impact” of COVID-19 on

parenting, family relationships, physical and emotional well-being, and overall distress. Scores are calculated as the mean of the 10, four-point Likert scale items. Two distress items (10-point scale) are reported separately and combined to give an average “family distress” score. Part 3: An open-ended question, “Please tell us about other effects of COVID-19 on your child/ren and family both positive and negative.” Internal reliability for CEFIS has been found to be excellent with a strong factor structure and clinical utility.⁶ For this study, internal consistency was low ($\alpha = .56$) for Exposure and acceptable ($\alpha = .74$) for Impact.

2.4.2 | Experience of Care (EoC) Survey

The EoC survey was developed by an expert multidisciplinary team of RCH pediatric clinician-researchers to assess the impact of COVID-19 and was adapted specifically for oncology families. The survey included: 19 items regarding access to health care, impact on treatment plans, hospital visitor restrictions and education; 24 items asking about their child’s exposure to PPE, COVID-19 testing (swabbing) and related distress; and two items regarding parent knowledge of COVID-19 and prevention measures, along with rankings of information sources and how trusted these were. All items were closed statements (yes/no, frequency counts), with some open-ended text to allow for further detail.

2.4.3 | McMaster Family Assessment Device (MFAD)

Parents completed the General Functioning Scale (GF) of the Family Assessment Device, a 12-item measure of overall healthy/unhealthy family functioning.^{7,8} Each item is rated (1–4) depending on how well it describes their family; scores are totaled and divided by the number of items. Higher scores reflect poorer family functioning. The GF has been shown to have good reliability and validity.⁹ Internal consistency for this measure was $\alpha = .88$.

2.5 | Statistical analysis

Descriptive statistics for all survey variables were calculated in SPSS Version 27¹⁰; specifically, means and standard deviations for continuous variables and frequency (%) and sample size for categorical variables. *t*-Tests and chi-square tests were used to compare completers and noncompleters across continuous and categorical variables, respectively. Internal consistency of the measures was calculated using Cronbach’s alpha and Kuder Richardson Formula 20. Examination of the associations between CEFIS Exposure, Impact and Distress scores was conducted using Pearson Product Moment Correlations. Regression analysis examining associations between specific child illness and family demographic factors and CEFIS Impact and Family Distress Scores were conducted in Stata 15¹¹ in order to impute missing data using the methods of multiple imputation. Twenty complete datasets were imputed via chained equations.¹² Estimates

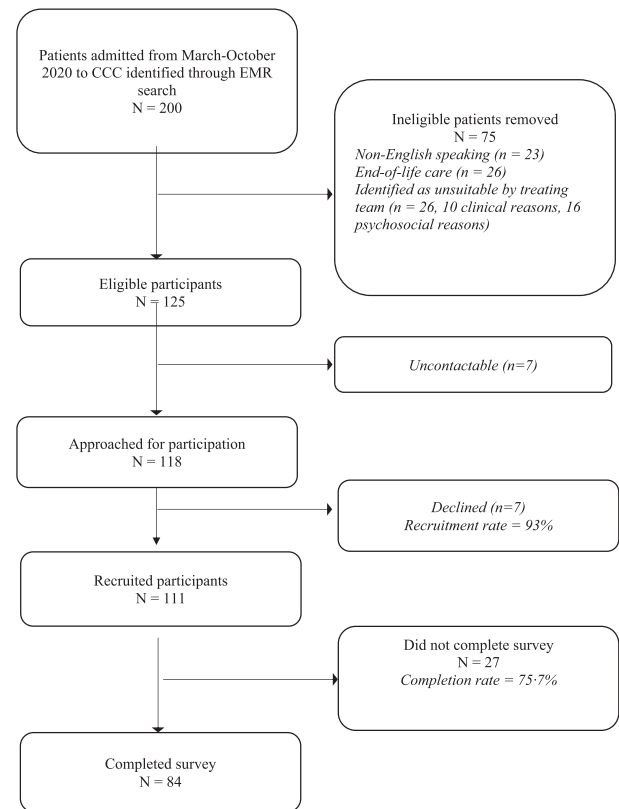


FIGURE 1 Recruitment flowchart

were then obtained by pooling results using Rubin’s rules.¹³ Prior to regression, all continuous variables were standardized (z-scores). Analyses were conducted separately for CEFIS Impact and Family Distress Scores; first as univariate linear regression models in which each independent variable was entered separately, and then as a single multivariable linear regression model in which all variables were entered simultaneously to remove any collinearity.

Open-text box data from the CEFIS and EoC survey were entered into QSR International’s NVivo 12 software to facilitate coding and analysis.¹⁴ Qualitative data were initially reviewed and discussed by two authors (Maria C. McCarthy and India R. Marks) to identify initial codes. Data were initially coded deductively into negative and positive effects. Inductive content analysis was utilized to identify emergent themes from additional open-ended text responses.¹⁵ NVivo coding comparison showed excellent inter-rater agreement; kappa = .82. Frequency counts were used to identify the weight of themes within the open-text responses.

3 | RESULTS

A total of 125 eligible participants were identified, 118 parents were approached to participate (seven were uncontactable), and 84 (76%) completed the survey within the 4-week study period (Figure 1). There were no significant differences between completers and noncompleters for child age, sex, age at diagnosis, diagnosis

category, time on treatment, and geographical location ($p > .1$). Table 1 provides participant demographics and medical details. Study participants were predominantly mothers (95%, $n = 80$). Most patients were diagnosed pre-COVID (67%), had acute lymphoblastic leukemia (ALL; 44%, $n = 37$), were admitted to hospital eight or more times (46%, $n = 39$), and spent 1 week or more in hospital (54%, $n = 43$).

3.1 | Exposure and Impact of COVID

The mean number of COVID-19 exposure items endorsed on the CEFIS was 7.42 (range 0–25). All families were exposed to stay-at-home orders, with additional exposure items endorsed relating to educational impacts: schools closed (92%, $n = 77$) and education disrupted (83%, $n = 70$); financial and work impacts: someone kept working (essential personnel, 41%, $n = 34$); work hours cut back (61%, $n = 51$); required to stop working (36%, $n = 30$); family income decreased (57%, $n = 48$); and family visitation: inability to visit or care for a family member (82%, $n = 69$). Three (4%) participants had a family member who had been exposed to someone with COVID-19 (father, grandparent, and patient). One participant had a family member diagnosed with COVID-19 (2-year-old patient). No respondents reported having a family member admitted to intensive care or die due to COVID-19.

Many families (76%) reported negative impacts of COVID-19 on family life ($M = 2.91$, $SD = 0.57$) across all domains except for “how family members got along with one another” (Figure 2). Parents rated their distress higher ($M = 6.35$, $SD = 2.11$) than their child’s ($M = 5.52$, $SD = 2.38$), $t(81) = 3.18$, $p = .002$, with combined Family Distress averaged as $M = 5.93$ ($SD = 1.91$). Correlations between the CEFIS subscales, Exposure and Impact ($r = .22$, $p = .049$), and between Family Distress and Exposure ($r = .23$, $p = .036$) were statistically significant but of low magnitude. Family Distress and Impact ($r = .534$, $p < .001$) were moderately and significantly correlated.

3.2 | Knowledge and information seeking

Most parents were confident in their knowledge about COVID-19 ($M = 5.84$, $SD = 1.01$; 1 = *very poor* to 7 = *very good*), as well as knowledge about how to prevent its spread ($M = 6.31$, $SD = .82$; 1 = *very poor* to 7 = *very good*). Most parents reported seeking COVID-19 information from reliable sources such as government websites, television, and newspapers. Most participants trusted the information they received from medical professionals (92%, $n = 77$), scientists (85%, $n = 71$), and state government sources (82%, $n = 69$); with the media the least trusted (29%, $n = 25$) (Supporting Material, Figures S1 and S2).

3.3 | Perception of hospital and oncology care during COVID-19

Most parents reported that their child felt safe in the hospital, with 25% ($n = 20$) reporting their child found it *only slightly* frightening

TABLE 1 Demographic characteristics

	N (%)	
Parent	84	
Relationship to child		
Biological mother	80	(95)
Biological father	4	(4.8)
Marital status, n (%)		
Single	4	(4.8)
Married	63	(75)
Defacto relationship/living together	13	(16)
Separated/divorced	4	(4.8)
Language other than English spoken at home		
Yes	23	(27)
No	61	(73)
Highest education/qualification completed		
University postgraduate qualification	24	(29)
University bachelor's degree	27	(32)
Trade certificate, diploma, or apprenticeship	22	(26)
None of the above	11	(13)
Australia as country of birth	47	(56)
Geography		
Metro	59	(70)
Regional	19	(23)
Interstate	6	(7.2)
Child		
Child sex		
Male	51	(61)
Female	33	(39)
Age (years) at time of participation, M (SD)	8.13(4.42)	
Age (years) at diagnosis, M (SD)	6.69(4.50)	
Time (years) on active treatment, M (SD)	1.05(0.56)	
Diagnosis at time of lockdown (State of Emergency declared March 16, 2020)		
Before lockdown	56	(67)
After lockdown	28	(33)
Number of hospital admissions		
1–3	28	(33)
4–7	17	(20)
8+	39	(46)

(Continues)

TABLE 1 (Continued)

<i>Child</i>		
Length of admission (N=80)		
Day procedure	24	(30)
Admission less than 1 week	13	(16)
Admission 1 week or more	43	(54)
Cancer diagnosis		
Acute lymphoblastic leukemia	37	(44)
Brain	15	(18)
Sarcoma	8	(9.5)
Lymphoma	7	(8.3)
Acute myeloid leukemia	5	(6.0)
Wilms tumor	3	(3.6)
Other solid tumors	3	(3.6)
Bone marrow transplant (pre-malignant and autoimmune disorder)	2	(2.4)
Anaplastic anemia	2	(2.4)
Other (immune deficiency disorders)	2	(2.4)

and 48% ($n = 38$) reporting it was *not at all* frightening; two parents (3%) reported their child found the hospital *extremely frightening*. Most parents (87%) perceived the hospital as *safe* (29%, $n = 24$) or *safer* (58%, $n = 49$) than before the pandemic. Similarly, of the parents who accessed the emergency department, the majority attended without hesitation (88%, $n = 64$). Nine parents (12%) were reluctant to attend the emergency department: four to avoid their child being swabbed; two to avoid exposure to COVID-19; one because their child was COVID-19 positive; one because the emergency department was full; one gave no reason.

Most parents reported no change to their child's care due to COVID-19; 69% ($n = 57$) reported no change to their child's treatment plan and 71% ($n = 59$) reported no delay in procedures or treatment. For those reporting a change (15%, $n = 12$), only three believed this compromised their child's treatment. Over 90% of parents (92%, $n = 76$) were confident that COVID-19 had no impact on medical decision-making. Of the 56 families (67%) whose child was diagnosed before COVID-19, 9% ($n = 5$) felt their oncology care was worse due to the pandemic. All parents reported an overall positive relationship with their child's care team, with 93% ($n = 76$) rating the relationship as *good* and 7% ($n = 6$) as *satisfactory*. Parents' overall positive perception of their child's medical care was also reflected in the majority of open-text survey responses (Table S1).

Oncology support services such as social work, mental health, art/music therapy, and education continued to be accessed by 57% of parents ($n = 48$). However, more than over one-third (39%, $n = 33$) reported some difficulty accessing services. Of those that accessed services, the majority were accessible face-to-face. Education services and social work provided many consultations via tele-

health/telephone (60% and 40%, respectively), with approximately one-fifth of parents (19%, $n = 16$) finding this less satisfying than face-to-face.

3.4 | COVID-19-related care changes

Nearly two-thirds of parents (62%, $n = 52$) reported their child was exposed to health professionals in full PPE with the majority "*not at all*" distressed by PPE (71%, $n = 37/52$). Eighteen patients (21%) experienced full PPE over 10 times a day.

COVID-19 swabs were mostly performed on asymptomatic children (63%, $n = 53$) prior to a procedure (i.e., lumbar puncture or surgery), while fever/temperature (21%, $n = 18$) and runny nose/cough (19%, $n = 16$) were other common reasons. The total number of swabs ranged from one to more than 20 swabs (median = 5). According to parents, more than half of the children experienced some distress prior to swabbing (56%, $n = 45$), one-third were "*quite*" or "*extremely*" distressed during the procedure (39%, $n = 33$) and over one-quarter (27%, $n = 23$) were "*not at all distressed*." The most common signs of distress were being upset, crying, and/or screaming. Children 8 years and under ($M = 3.71$, $n = 42$) were significantly more distressed than children 9 years and older ($M = 1.97$, $n = 39$), $t(70) = 6.16$, $p < .001$. Twenty families reported their child needed to be restrained during swabbing (24%) and over one-quarter of parents (27%, $n = 24$) reported their child required procedural support from Child Life therapists. Over two-thirds of parents reported feeling *quite prepared* or *very prepared* for their child's swabbing procedure (71%, $n = 57/80$), while three parents (4%) reported they were unprepared. Most parents were not distressed about their child's COVID swabs; however, nine (11%) reported being *extremely distressed*.

According to parent reports, most children were impacted by hospital restrictions and the one caregiver policy during their admission (68%, $n = 57$); one-quarter (26%, $n = 22$) reported no impact and 2% ($n = 2$) were unsure. Over two-thirds of parents (71%, $n = 60$) indicated they were personally impacted by these restrictions. These results were also reflected in open-text responses in which parents most frequently commented on the negative impacts of visitor restrictions and separation from family and social supports (Table 3). Parents also expressed worry about their ill child contracting the virus, financial issues, and difficulties accessing some health care/charity services. Parents reported some positive impacts of COVID-19, which included increased quality family time, greater community hygiene standards, ability to work from home, and children's adjustment to online learning.

3.5 | Correlates of CEFIS Impact and Family Distress

The results of univariate and multivariable regression analyses examining associations between a selected set of child illness and family demographic factors and CEFIS COVID-19 Impact and Distress scores

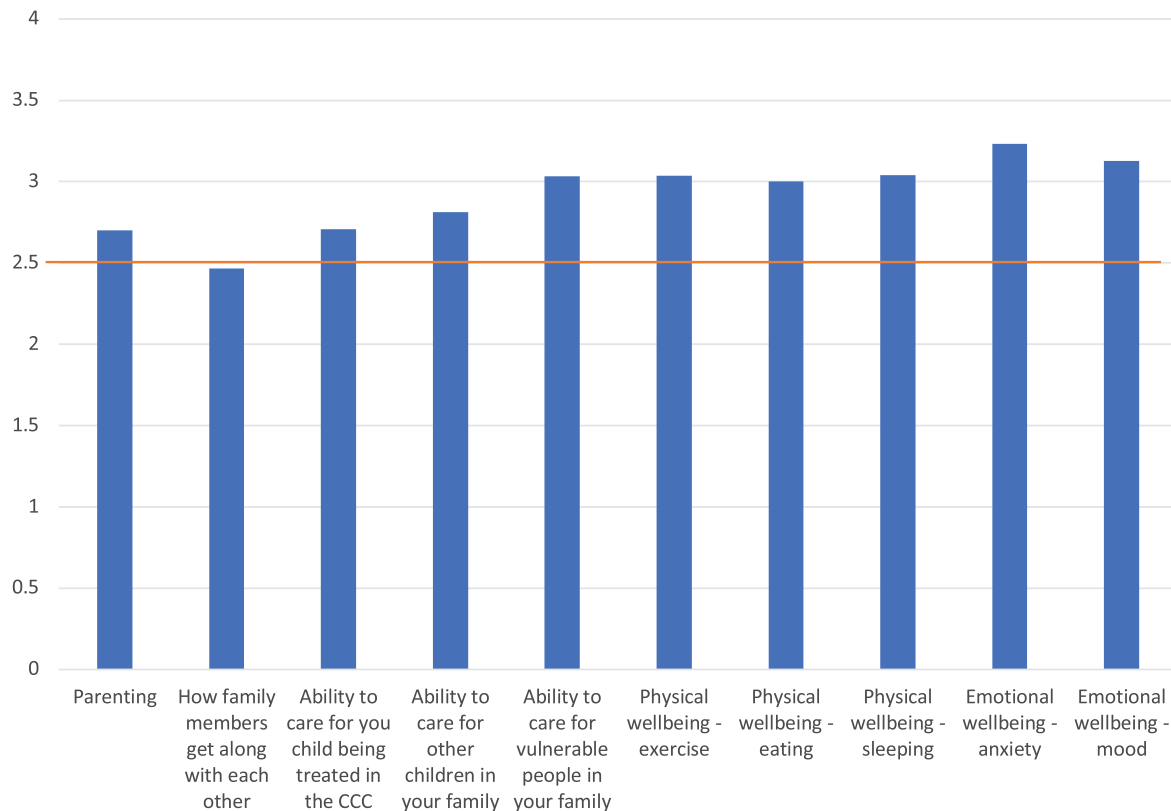


FIGURE 2 Mean scores on COVID-19 Exposure and Family Impact Survey (CEFIS) impact items. Scores >2.5 indicate negative impact

are presented in Table 2. Increasing family dysfunction (MFAD) was associated with greater COVID-19 impact, while having a parent born outside Australia was associated with *less* overall COVID-19 impact and family distress. No other variables were found to be significantly associated with the CEFIS Impact and Distress outcome variables.

4 | DISCUSSION

This is the first Australian published study to report on parent perceptions of their child's cancer care during the COVID-19 pandemic. Parent participation coincided with a 161-day lockdown period, involving stringent community and hospital restrictions. Two-thirds of parents included in this study had a child diagnosed prior to the pandemic; the remaining parents were diagnosed during lockdown. All children were receiving active cancer treatment at the time of the study.

In addition to stay-at-home orders, parents endorsed work/financial changes and changes to child education as the most frequent COVID-19-related disruptions. Parents reported negative impacts across a range of domains, with parenting (their ability to care for their sick child and siblings) and self-care (parents' own physical and emotional well-being) the domains most impacted. These findings are similar to the exposure and impact findings recently reported by Kazak et al. (2021), despite significantly higher rates of COVID-19 in the United States.

In both studies, parents endorsed their personal well-being, particularly anxiety and mood, as the most negatively impacted domains. These results suggest that measuring parents' subjective appraisals of COVID-19-related impacts may be important to guide psychosocial supports for families who are navigating not only the pandemic but also the stressors associated with their child's illness.

Most child illness and family demographic variables examined were not associated with parent-reported COVID-19 impact or family distress, including whether a child was diagnosed pre- or during the COVID-19 lockdown period. Of note, however, poorer family functioning was associated with increased COVID-19 family impact. These findings are consistent with traumatic stress models, which posit the importance of psychosocial factors rather than illness and demographic factors in predicting outcomes.¹⁶ This finding also suggests that psychosocial interventions directed at strengthening family functioning and relationships may be helpful in mitigating the additional stressors families with children with cancer are navigating because of COVID-19. An unexpected finding was that parents who were born outside Australia reported less COVID-19 impact and family distress. It is possible that this finding reflects the resilience of families who undertake migration to a new country. Of note, many families migrate to Australia as skilled workers, and can access universal education and health care systems; this may be reflected in our study sample. The experience of refugee families, however, is likely to be very different. Further examination of COVID-19 impacts on

TABLE 2 Univariate and multivariable associations between child, treatment and family characteristics and mean CEFIS Impact and Family Distress Scores

	Mean CEFIS Impact Score				Mean CEFIS Family Distress Score			
	Univariate		Multivariable		Univariate		Multivariable	
	β	95% CI	p		β	95% CI	p	
Child Characteristics								
Age (at participation)	-.10	(-0.32, 0.12)	.357	-.13	(-0.36, 0.10)	.254	.10	(-0.12, 0.32) .371 .02 (-0.21, 0.24) .865
Female	(base)						(base)	
Male	-.04	(-0.49, 0.41)	.857	.05	(-0.41, 0.51)	.843	.09	(-0.36, 0.55) .678 .13 (-0.33, 0.60) .566
Treatment Characteristics								
Diagnosis Prior to Lockdown	(base)						(base)	
Yes								
No	.30	(-0.16, 0.76)	.199	-.04	(-0.74, 0.65)	.898	.11	(-0.36, 0.58) .639 -.4 (-1.11, 0.30) .254
Time on Active Treatment	-.09	(-0.31, 0.13)	.417	-.09	(-0.40, 0.23)	.589	-.19	(-0.41, 0.03) .091 -.28 (-0.60, 0.04) .089
Number Hospital Admissions During Lockdown	-.05	(-0.28, 0.19)	.700	-.07	(-0.30, 0.16)	.564	.02	(-0.23, 0.27) .850 .01 (-0.23, 0.24) .964
Family Characteristics								
Maternal Education	(base)						(base)	
No tertiary education/trade								
Trade, diploma, apprentice	.40	(-0.35, 1.14)	.292	.49	(-0.23, 1.21)	.179	.58	(-0.14, 1.30) .113 .67 (-0.05, 1.39) .068
University	.37	(-0.35, 1.09)	.304	.62	(-0.10, 1.35)	.091	.04	(-0.66, 0.73) .916 .23 (-0.50, 0.96) .531
PostGraduate degree	.17	(-0.56, 0.90)	.652	.31	(-0.43, 1.05)	.407	-.21	(-0.91, 0.50) .564 -.13 (-0.87, 0.61) .726
Australian Born								
Yes	(base)						(base)	
No	-.59	(-1.01, -0.16)	.007	-.77	(-1.23, -0.31)	.001	-.50	(-0.94, -0.07) .025 -.57 (-1.03, -0.11) .017
MFAD score	.16	(-0.06, 0.38)	.145	.26	(0.03, 0.49)	.026	0	(-0.22, 0.23) .976 .05 (-0.18, 0.27) .683

Abbreviation: MFAD, McMaster Family Assessment Device.

TABLE 3 Parent comments from the COVID-19 Exposure and Family Impact Survey (CEFIS)

Theme	No. of comments	Illustrative quotation(s)
<i>Negative effects</i>		
Family separation and loss of support One parent caregiver	33	COVID-19 caused a lot of social isolation for our family during a very significant part of [child name] treatment. As a single parent the lockdown took away all forms of support I had available to cope with managing being a sole parent and full-time worker. Prior to COVID, we relied on [child name] grandparents for assistance with medical appointments and emotional support regarding [child name] illness. We were essentially alone during the most difficult time in our lives. Major psychological distress been unable to parent and look after our sick child together. The time we spent in hospital was unbearable, the strain of being alone with your sick child while processing a life-changing diagnosis made everything feel so much harder. My partner and I did not see each other for 2 weeks other than handing over our hospital pass in front of a security guard when we swapped over in the foyer of RCH.
Disruption of normal routines and activities	13	Having two adults working from home and four kids in remote learning in a four-bedroom house was a real challenge for everyone. The kids were not learning as much as they could cause they were preoccupied with playing at home. Not being able to go to a playground, not having space, being able to travel - even a little
COVID-19-related fear and anxiety	11	The family are a little frightened to leave the house because we don't want to bring any illness home to [child name]. Each time when [child name] had fever, I was so worried that we would get COVID at the Emergency. We were very stressed, scared, and anxious about keeping [child name] safe.
Social isolation	10	Mostly involving [child name] already spending so much time away from school he has lost his confidence and spark. My older child has struggled greatly with not seeing friends. We have missed social interactions with people outside the home.
Difficulty accessing to health care and charity services	6	[Child name] rehab was also significantly affected. Telehealth is not possible with a 3-year old. [Child name] is most saddened by the closure of the Starlight Room and the lack of volunteers and visitors who use to roam the ward and provide a welcome distraction for the kids. There is definitely a more intense feeling of isolation when staying on the wards under COVID.
Work/financial implications	4	Major income was lost. I had to stop working at my second job due to lockdown and my son's diagnosis. This reduced our income, which caused a bit of stress financially.
COVID swabbing	4	[Child name] has had nine COVID swabs. All for protocol not because she had any symptoms. [Child name] need to be tested of COVID-19 always before going to theatre, which really disturbed her on every take.
Strained interpersonal relationships	4	Keeping us all together during this time has been very important but has also had a toll on our relationship, but we will get through it. The kids were fighting with each other because they were bored at home.
<i>Positive effects</i>		
Increases in spending quality family time together	11	It has been positive to connect as a family in new ways (e.g., movie nights at home, bike riding). Was a chance to bond as a family, be present with [child name] as parents, focus less on material possessions and more on doing things such as cooking as a family.
Adjustment to online learning	9	Overall, they adjusted to home learning well and in some ways this was good for [child name] while had daily radiotherapy, he kept up with his school work. Schooling has been fantastic both with not having to do pick ups and drop offs and knowing that the younger child will not bring any illness home and his overall study and marks have improved.
Work from home	6	Also, the time I wasn't able to work meant I could take [child name] to more medical appointments than I otherwise might have been able too. Husband works from home so that he is able to share [child name] cares.
Extra hygiene	4	COVID has also offered a great reason for everyone to be extremely hygienic and wear face masks, which has meant it is not all about [child name] illness and is helping keep him safe, we hope this takes away some of his burden. To people a runny nose wasn't a big deal but to [child name] it could be. Now it's big deal for everyone.

immigrant and refugee families is warranted given this preliminary finding.

Most parents reported feeling knowledgeable about COVID-19, obtaining information from multiple trusted sources including government sources and health care providers. This is in contrast to a recent study from the United Kingdom, which found parents mostly obtained information via cancer charities and reported unmet information needs particularly related to childhood cancer.¹⁷ These differences may relate to different approaches to information provision; for example, the Victorian Government and health officials held daily news conferences during lockdown. Additionally, the hospital provided regular online COVID-19 updates in multiple languages, while oncology-specific information was delivered to families via the patient portal.

Importantly, many parents reported feeling safer or as safe in the hospital environment compared to pre-COVID-19. Very few delayed hospital attendance due to safety concerns, which is in contrast to findings reported by Darlington et al.,¹⁷ where two-thirds of parents of children with cancer no longer considered hospital a safe place. Parents also perceived few delays or compromises in their child's care throughout the pandemic, with only a small number of parents (9%) whose children were receiving cancer care prior to the pandemic reporting that care was worse. Findings from this study are in contrast to other patient and family studies^{17,18} and a recent American study of 13 pediatric oncology institutions across New York and New Jersey, which identified significant delays in treatment including chemotherapy (54%), surgery (46%), and transplant (30%).¹⁹ Similar findings related to delays in treatment have been reported internationally.^{20,21}

Australia's COVID-19 infection rates have been low relative to other countries. Early in the pandemic, the RCH implemented strict policy changes and, despite Victoria being the most impacted Australian state, the RCH itself has had few COVID-19-positive inpatients ($n = 21$). It is possible these factors contributed to most families feeling safe within the hospital. Importantly, although specialist COVID-19 testing and respiratory services were introduced, other services such as elective surgery were reduced and outpatient appointments converted to telehealth, meaning the hospital was not overwhelmed by patient demand during this period. In addition, pediatric oncology clinical trials continued, with no studies closed due to lockdown. These factors potentially contributed to oncology services continuing with minimal delays.

Australia implemented strict screening and COVID-19 testing measures, especially for those with cold/flu-like symptoms. As a result, RCH oncology patients underwent multiple swabbing, a procedure recognized for its discomfort. Many children in this study were distressed by swabbing, especially younger children, which is consistent with existing knowledge on procedural distress.²² Almost a quarter of the sample reported their child had to be restrained, potentially creating another level of distress. These results are concerning given children with cancer already undergo multiple invasive medical procedures and early experiences of difficult and painful procedures can have significant short- and long-term impacts.²³ Whether this testing has led to greater procedural distress in oncology patients or will have persistent longer

term effect is, as yet, unknown. Importantly, future studies need to focus on the long-term effects of swabbing (i.e., trauma and distress) for this population.

There are several limitations of this study. First, this is a single-institution study; therefore, generalizability of findings is limited. However, given Victoria was impacted more than any other Australian state during this period, this study likely represents the "worst-case scenario" with respect to the impact of COVID-19 on Australian pediatric oncology patients receiving active treatment. Second, the data presented include only parent reports; it is possible oncology health care providers and children themselves have different perspectives on the quality of cancer care during the pandemic. Third, the study was limited to parents whose children were actively receiving treatment, and may have excluded patients who experienced treatment delays, such as children awaiting donor transplants.²⁴ Additionally, non-English speaking parents were excluded from the study, as were families whom clinicians deemed unsuitable to approach, often due to psychosocial complexities. These groups likely represent significantly vulnerable subgroups and thus our findings may underestimate COVID-19-related distress. Another limitation is that the internal reliability of the CEFIS exposure subscale was low in contrast to the recently reported psychometrics of this new measure. Finally, this paper has not included additional data that examined patient and parent distress, the impact of hospital restrictions, social isolation, and reduced support from volunteers and cancer charities. The finding that approximately one-third of parents in this study reported difficulty accessing allied health and support services suggests that while medical care continued, families may have been less supported regarding psychological and physical burdens. Additional data, which are currently being analyzed for publication, may assist oncology health care providers and support organizations to identify, and potentially mitigate, the longer term psychological sequelae of these experiences in this vulnerable population.

In conclusion, this study has identified that despite enduring some of the strictest lockdown measures worldwide, most pediatric oncology parents were pleased with the quality of their child's care during the COVID-19 pandemic. Access to COVID-19 information that was both trusted and specific to pediatric cancer and strict public health measures, which kept community and hospital infection rates manageable, possibly contributed to parent's perceptions of a safe clinical environment. Importantly, there was minimal impact on pediatric oncology care during lockdown. Despite these positive findings, family well-being was overall negatively impacted and the psychological impact of COVID-19 in this cohort will be important to explore in more detail to fully understand the child and family experience, particularly given pre-existing stressors associated with childhood cancer diagnosis.

ACKNOWLEDGMENTS

This study was supported by the Victorian Government's Operational Infrastructure Support Program. Maria C. McCarthy is supported by a Victorian Cancer Agency Mid-Career Fellowship. We gratefully acknowledge the generosity of all study participants and the contributions of A/Prof. Margie Danchin and Dr. Jessica Kaufman.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

ETHICS STATEMENT

The study was granted ethical approval by the Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC/63636/RCHM-2020-216823).

AUTHOR CONTRIBUTIONS

Maria C. McCarthy, Cinzia R. De Luca, Tria Williams, and Catherine M. Bauld conceptualized the study. Maria C. McCarthy and Jessica Beamish contributed to the literature search. Maria C. McCarthy, Cinzia R. De Luca, and Jessica Beamish were responsible for data collection. Maria C. McCarthy, Craig A. Olsson, Cinzia R. De Luca, India R. Marks, and Jessica Beamish conducted data analyses. All authors contributed to the interpretation of the findings. Maria C. McCarthy wrote the first draft of manuscript. All authors contributed to revision and editing, and approval of the final submitted version. All authors accept responsibility for the decision to submit for publication.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Maria C. McCarthy  <https://orcid.org/0000-0001-6543-3921>

Cinzia R. De Luca  <https://orcid.org/0000-0002-9310-1833>

REFERENCES

- Bouffet E, Challinor J, Sullivan M, Biondi A, Rodriguez-Galindo C, Pritchard-Jones K. Early advice on managing children with cancer during the COVID-19 pandemic and a call for sharing experiences. *Pediatr Blood Cancer*. 2020;67(7):e28327.
- Sullivan M, Bouffet E, Rodriguez-Galindo C, et al. The COVID-19 pandemic: a rapid global response for children with cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI, and St Jude Global. *Pediatr Blood Cancer*. 2020;67(7):e28409.
- Balduzzi A, Brivio E, Rovelli A, et al. Lessons after the early management of the COVID-19 outbreak in a pediatric transplant and hemato-oncology center embedded within a COVID-19 dedicated hospital in Lombardia, Italy. *Estote parati. Bone Marrow Transplant*. 2020;55(10):1900-1905.
- Casanova M, Pagani Bagliacca E, Silva M, et al. How young patients with cancer perceive the COVID-19 (coronavirus) epidemic in Milan, Italy: is there room for other fears? *Pediatr Blood Cancer*. 2020;67(7):e28318.
- Harris PA, Thielke R, Taylor R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381.
- Kazak AE, Alderfer M, Enlow PT, et al. COVID-19 Exposure and Family Impact Scales: factor structure and initial psychometrics. *J Pediatr Psychol*. 2021;46(5):504-513.
- Miller IW, Bishop DS, Epstein NB, Keitner GI. The McMaster Family Assessment Device - reliability and validity. *J Marital Fam Ther*. 1985;11(4):345-356.
- Mansfield A, Keitner G, Dealy J. The Family Assessment Device: an update. *Fam Process*. 2015;54(1):82-93.
- Byles J, Byrne C, Boyle MH, Offord DR. Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Fam Process*. 1988;27(1):97-104.
- IBM Corp. IBM SPSS Statistics for Windows, Version 27.0. IBM Corp; 2020.
- StataCorp. Stata Statistical Software: Release 15. StataCorp; 2017.
- Lee KJ, Carlin JB. Multiple imputation for missing data: fully conditional specification versus multivariate normal imputation. *Am J Epidemiol*. 2010;175(5):624-632.
- Rubin DB. In: *Multiple imputation for nonresponse in surveys*. Wiley Series in Probability and Statistics. United States: John Wiley and Sons; 1987.
- NVivo Qualitative Data Analysis Software [Software] [computer program]. 1999. <https://qsrinternational.com/nvivo/nvivo-products>. Accessed January 21, 2021.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101.
- Price J, Kassam-Adams N, Alderfer MA, Christofferson J, Kazak AE. Systematic review: a reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *J Pediatr Psychol*. 2015;41(1):86-97.
- Darlington A-SE, Morgan JE, Wagland R, et al. COVID-19 and children with cancer: parents' experiences, anxieties and support needs. *Pediatr Blood Cancer*. 2021;68(2):e28790.
- Mirlashari J, Ebrahimpour F, Salisu WJ. War on two fronts: experience of children with cancer and their family during COVID-19 pandemic in Iran. *J Pediatr Nurs*. 2020;57:25-31.
- Madhusoodhan PP, Pierro J, Musante J, et al. Characterization of COVID-19 disease in pediatric oncology patients: the New York-New Jersey regional experience. *Pediatr Blood Cancer*. 2021;68(3):e28843.
- Saab R, Obeid A, Gachi F, et al. Impact of the coronavirus disease 2019 (COVID-19) pandemic on pediatric oncology care in the Middle East, North Africa, and West Asia region: a report from the Pediatric Oncology East and Mediterranean (POEM) group. *Cancer*. 2020;126(18):4235-4245.
- Vasquez L, Sampor C, Villanueva G, et al. Early impact of the COVID-19 pandemic on paediatric cancer care in Latin America. *Lancet Oncol*. 2020;21(6):753-755.
- McCarthy M, Glick R, Green J, et al. Comfort first: an evaluation of a procedural pain management programme for children with cancer. *Psychooncology*. 2013;22(4):775-782.
- Flowers SR, Birnie KA. Procedural preparation and support as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(S5):S694-S723.
- Gillam L, Spriggs M, Delany C, Conyers R, McCarthy M. Telling the truth to child cancer patients in COVID-19 times. *J Bioethical Inq*. 2020;17(4):797-801.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: McCarthy MC, Beamish J, Bauld CM, et al. Parent perceptions of pediatric oncology care during the COVID-19 pandemic: An Australian study. *Pediatr Blood Cancer*. 2021:e29400. <https://doi.org/10.1002/pbc.29400>.