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RESEARCH ARTICLE

Quality of life and family functioning 12 months after diagnosis of childhood brain tumour: A longitudinal cohort study

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Abstract

Background: The wellbeing of a child with brain tumour is affected by several factors. We present the first investigation of quality of life and family functioning in a parent and child across the first 12 months after diagnosis, examining potential factors to guide the provision of psychosocial resources to families who most need them.

Procedure: Data were collected from parents/carers in Queensland, Australia, from 2020 to 2023. Child (parent/carer-proxy reported) and carer quality of life was assessed across three timepoints (repeated measures analysis of variance [ANOVA]) and by five potential co-variates (mixed between-within ANOVA). Family functioning was assessed across two timepoints (repeated-measures *t*-test), and by potential co-variates (repeated measures ANOVA). Univariate relationships were explored with Pearson's correlation coefficient; significant relationships were entered into multiple regression models.

Results: Ninety-six diverse families were represented. Quality of life (child, carer) and family functioning did not change across time. Children from households with lower income reported worse cognitive difficulties ($p = .023$) and pain and hurt ($p = .013$) than those from a higher income. Caregiver quality of life was poorer for those whose child had received chemotherapy and/or radiation, was aged less than 4 years at diagnosis, and had a lower household income. At 12 months, caregiver quality of life was correlated with family functioning ($r = -.45$, $p < .001$), with positive adaptation being a significant key predictor ($beta = -.66$, $p < .005$).

Conclusions: The following factors indicate a need for increased early psychosocial support: cognitive difficulties, aged <4 years at diagnosis, receiving chemotherapy and/or radiation, and low household income.

KEYWORDS
brain neoplasm, family functioning, paediatrics, quality of life, survey

Abbreviations: ANOVA, analysis of variance; CQOLC, Caregiver Quality of Life Index-Cancer scale; FAD-GFS, Family Assessment Device General Functioning subscale; QCH, Queensland Children's Hospital; RQ, research question.

Although childhood cancer is widely understood to be a challenging experience for the child and their family, those diagnosed with brain tumour have unique additional challenges.[1,2] The brain is essential to the functioning of the human body and to the experience of life. A tumour in this area in childhood—a pivotal point in cognitive, physical and emotional development—produces challenges to treatment and impacts development.[1,2] Current 5-year survival rates have reached approximately 77% in Australia,[3] and these children often experience long-term effects to their development, such as memory deficits and impaired mobility,[1] creating additional caring responsibilities for parents.[4] Non-malignant brain tumours also produce significant risks to the livelihood of children.[1] In the broader childhood cancer literature, scholars typically describe that many families, while distressed, adapt to the challenges of diagnosis, treatment and survivorship or bereavement.[5,6] Few studies, however, have focused specifically on the experiences of those living with paediatric brain tumour, despite the unique challenges of this diagnosis.

From diagnosis, caring for a child with a brain tumour has significant psychosocial impact for parents or other carers.[4] Although characteristics of a child's clinical condition are related to their parents' quality of life, research suggests this is mediated by caregiver burden and stress.[7] Adaptive family functioning—defined by cohesiveness, effective communication and low conflict—following treatment protects against long-term adverse psychosocial outcomes for paediatric brain tumour survivors.[8,9] Socioeconomic factors, such as household income and social support systems, are known to contribute to families' overall adjustment, functioning and wellbeing within childhood cancer more broadly.[5,9,10] Overall, there is a complex web of biopsychosocial variables that influence the outcomes and experiences of the child and their family.[6,11] There has been little scholarly investigation into quality of life in children with brain tumour and their carers, and how this relates to overall family functioning, in the early stages of the cancer experience.

The purpose of this paper is to investigate quality of life and family functioning in a longitudinal survey of families recruited from a statewide paediatric tertiary health service in Australia. Specifically, we looked to locate factors that may guide the provision of psychosocial resources to families who most need them. Families were followed at three timepoints (<3 months, 6 months, 12 months) after their child's diagnosis of a brain tumour. Informed by previous scholarly literature, we developed the following research questions (RQs):

RQ 1: Does quality of life (caregiver, diagnosed child) and family functioning change over the first 12 months post-diagnosis?
RQ 1a: Does this vary by clinical and sociodemographic factors?
RQ 2: Does child quality of life soon after diagnosis predict caregiver quality of life 12 months post-diagnosis?
RQ 2a: If so, which elements of child quality of life are most predictive?
RQ 3: Is there a relationship between caregiver quality of life and family functioning at 12 months post-diagnosis?
RQ 3a: If so, which elements of caregiver quality of life explain the most variance in family functioning?

1 | METHOD

The study protocol was approved by the Children's Health Queensland Human Research Ethics Committee (HREC/19/QCHQ/53816).

1.1 | Overview

This paper is part of an ongoing longitudinal survey of parents/carers in the first 24 months after their child was diagnosed with a brain tumour—the current paper considers the first 12 months only. The methods of the larger project have been described elsewhere[12,13]; here, we provide a succinct description. Participants were recruited from the Queensland Children's Hospital (QCH), a tertiary public hospital located in the city of Brisbane in the state of Queensland, Australia. All children (0–14 years) and most adolescents (15–18 years) diagnosed with cancer in Queensland—approximately 300 per year—receive centralised oncology care through this hospital.

1.2 | Participants

Parents and carers of a child (aged 18 years or under) recently diagnosed with a malignant or non-malignant brain tumour were invited to complete the survey. We had originally planned to recruit participants 6 weeks or less after diagnosis, but due to Covid-19-related hospital access restrictions, we increased this to 3 months or less to increase our sample size. To participate, carers must have been at least 18 years old and able to read and understand English.

Our clinical research nurse (Author C) identified newly diagnosed families at the weekly Solid Tumour Service Multi-Disciplinary Team meetings and in consultation with treating clinicians. When appropriate, she approached a parent/carer in person at the hospital or over telephone to invite them to participate in the study, following established recruitment principles.[14] Families were deemed inappropriate to contact if treating clinicians suspected that such a request could cause undue burden (e.g., if their child was likely to die in the near future). Participants provided their written informed consent prior to completing the first survey—delivered through REDCap[15]—on our tablet device or on their own devices through an emailed link. All respondents represented separate families. Data analysed for the present paper were collected between January 2020 and July 2023.

1.3 | Measures

To reduce participant burden, we collected clinical and some demographic information from hospital records. We categorised each child's diagnosis into low or high grade based upon the WHO classification.[16] Measurements by survey timepoint are displayed in Table 1. Each timepoint (>3 months, 6 months, 12 months) was approximate; we aimed to survey participants at or around 2 weeks either side of these, recognising they were in a challenging and unstable experience.

TABLE 1 Survey timepoints, measurements and sample sizes.

	Time 1	Time 2	Time 3
Approximate time since diagnosis	<3 months	6 months	12 months
Measurements			
Demographics	x		
Child quality of life (parent/carer-proxy report)—PedsQL Brain Tumour Module	x	x	x
Caregiver quality of life—CQOLC	x	x	x
Family functioning—FAD-GFS	x		x
Sample size (*n*)	81	55	66

Abbreviations: CQOLC, Caregiver Quality of Life Index-Cancer; FAD-GFS, McMaster Family Assessment Device General Functioning subscale; PedsQL Brain Tumour Module, Brain Tumour Module Quality of Life Index.

1.4 | Child quality of life

Caregivers completed the Brain Tumour Module Quality of Life Index (PedsQL Brain Tumour Module) on behalf of their child.[17] This measure has no total score but six subscales: cognitive problems (for children aged at least 5 years); pain and hurt; movement and balance; procedural anxiety; nausea; worry. Subscales were scored as prescribed in Mapi Research Trust and Varni.[17] Each subscale had a total possible score of 100, with higher scores indicating less severe problems.

1.5 | Caregiver quality of life

Caregivers completed the 35-item Caregiver Quality of Life Index-Cancer (CQOLC) scale.[18] The CQOLC includes four subscales: burden; disruptiveness; positive adaptation; financial concern. Total and subscales scores were calculated as instructed in Duan et al.[19] The highest total possible score was 140, with higher scores indicating better quality of life.

1.6 | Family functioning

Family functioning was measured by the 12-item McMaster Family Assessment Device General Functioning subscale (FAD-GFS) and scored as outlined in Epstein, Baldwin and Bishop.[20] The highest possible total score is 4.0, with higher scores indicating more problematic functioning; a score of two or above is indicative of problematic family functioning.

1.7 | Data management and analyses

Potential co-variates were collapsed into binary variables to maximise statistical analyses for the sample size. Five were deemed clinically and theoretically relevant with sufficient group sizes: tumour risk (low/high),[16] treatment (surgery only/other or any chemotherapy and/or radiation), age at diagnosis (4 years or less/>4 years),[3] household income (<AU$70,000K/≥AU$70,000K), and distance home located from hospital (<50 km/≥50 km).[21] One-way repeated measures analysis of variance (ANOVA) was conducted for each outcome variable that was measured at all three timepoints (caregiver quality of life, child quality of life) to assess potential differences across time. Significant findings were further examined with post-hoc comparisons using the Tukey Honestly Significant Difference test. A repeated-measures *t*-test was used to assess family functioning as it was collected at two timepoints only (Time 1 and Time 3). Mixed between-within subjects ANOVA was used to assess quality of life by each potential co-variate across time; one-way repeated measures ANOVA was used for family functioning. Univariate relationships between variables were explored with Pearson's correlation coefficient. Those that were significant were then entered into either a standard or hierarchical multiple regression model, as appropriate.

Our findings are likely influenced by the stress and uncertainty of life during the Covid-19 pandemic.[22,23] We conducted sensitivity analyses comparing each outcome variable across the three survey timepoints by the year the participant completed their first survey (2020: onset of pandemic; 2021: strictest government regulations in place; 2022: restrictions largely removed[24]).

Preliminary analyses were conducted to ensure the data met relevant assumptions for each reported analysis. Missing data were managed as dictated in each scale's scoring instructions; pairwise exclusion of cases was applied for sociodemographic data. Statistical significance was set at a p value of .05 and confidence intervals calculated at a confidence level of 95%.

2 | RESULTS

Participants' clinical and sociodemographic variables are described in Table 2. We achieved a balance of tumour risk types, treatment received and age at diagnosis; but had more female caregivers (86%). Most (87.5%) caregivers were partnered and most (84.4%) families included more than one child. We had a greater percentage of people who identify as Aboriginal and/or Torres Strait Islander than in the general Queensland population (9.4 vs. 4.6%, respectively[25]). Forty-nine percent resided 50 km or more from the study hospital

TABLE 2 Participant clinical details and demographics.

Variable	Sample characteristics *N* = 96 *n* (%)
Tumour classification	
Low-grade brain tumour	49 (51.0)
High-grade brain tumour	47 (49.0)
Treatments received	
Surgery only	35 (36.5)
Any chemotherapy and/or radiation	50 (52.1)
Other (e.g., observation only, immunotherapy)	11 (11.5)
Age at diagnosis	
4 years and under	36 (37.5)
Range	3 months – 4 years
5 years plus	60 (62.5)
Range	5–17 years
Child sex	
Male	60 (62.5)
Female	36 (37.5)
Caregiver	
Male	10 (10.4)
Female	86 (89.6)
Parenting make-up	
Single parent	12 (12.5)
Parents coupled	84 (87.5)
Sibling make-up	
Only child	13 (13.5)
One or more siblings	81 (84.4)
Missing	2 (2.1)
Indigenous Australian[a]	
Yes	9 (9.4)
No	87 (90.6)
Location from treating hospital	
<50 km	49 (51.0)
≥50 km	47 (49.0)
Annual household income	
<70,000	24 (25.0)
≥70,000	38 (39.6)
Prefer not to say	18 (18.8)
Missing	16 (16.7)

[a]At least one member of the immediate family identified as Aboriginal and/or Torres Strait Islander.

and 25% declared a lower household income (<AU$70,000). A total of 96 parent/carers submitted surveys; however, 43 parent/carers contributed data at all three timepoints, and a further eight at only Time 1 and Time 3 (see Table 1). An additional 32 families were approached but declined to participate.

Our sensitivity analyses of the outcome measures by different timepoints in the Covid-19 pandemic found no statistically significant differences.

2.1 | Analysis of outcome variables by time (RQ 1)

Children's quality of life did not statistically change over time within 12-months post-diagnosis (Table 3). Caregiver quality of life also did not significantly change over this period; however, differences were observed for two subscales: burden and disruptiveness. Post-hoc comparisons indicated that caregiver burden improved between Times 1 and 2 ($p = .045$, CI: −3.369 to 0.027) and Times 1 and 3 ($p = .002$, CI: −4.556 to 0.839); however, Time 2 did not differ from Time 3. Disruptiveness improved from Time 1 and 3 ($p = .003$, CI: −3.882 to 0.689), and Time 2 and 3 only ($p = .049$, CI: −3.185 to 0.006). Mean family functioning did not differ between Time 1 and Time 3.

2.2 | Analysis of outcome variables by time and potential co-variates (RQ 1a)

Means and standard deviations for significant main and interaction effects for child and caregiver quality of life are presented in Table 4.

2.3 | Child quality of life

Cognitive difficulties did not significantly differ across time by tumour risk, treatment type or distance living from hospital. There was, however, a significant interaction between time and household income, Wilks' Lamba = 0.697, F (2, 21) = 4.564, $p = .023$, $\eta_p^2 = .30$. Children from a household reporting lower income demonstrated an increase in cognitive difficulties between Times 1 and 2 and a slight improvement at Time 3, while those from a household with higher income demonstrated a decrease in cognitive difficulties from Time 1 to Time 2 and a slight increase at Time 3 (Figure 1). The main effect of household income was also significant, F (1, 22) = 10.77, $p = .003$, $\eta_p^2 = .33$.

Pain and hurt did not differ by tumour risk, age at diagnosis or location from the hospital. There was, however, a main effect for treatment type, F (1, 41) = 10.65, $p = .002$, $\eta_p^2 = .21$, with those who received any chemotherapy and/or radiation reporting worse pain and hurt scores across all three timepoints. There was also a main effect for household income, F (1, 36) = 6.869, $p = .013$, $\eta_p^2 = .16$, with children from lower income households reporting increasingly worse pain and hurt at each timepoint, while children from higher income households reported a decrease in pain and hurt at Time 2 before increasing again at Time 3.

Movement and balance differed only by treatment received, F (1, 41) = 16.64, $p < .001$, $\eta_p^2 = .29$, with parent/carers of those who had had any chemotherapy and/or radiation reporting more concerning scores for their child at every timepoint.

Procedural anxiety did not significantly differ across time by tumour risk, treatment received, age at diagnosis, location from hospital or household income.

TABLE 3 Outcome variables for each data collection timepoint.

	Time 1: <3 months post dx		Time 2: 6 months post dx		Time 3: 12 months post dx				
	M	SD	M	SD	M	SD	*F*/*t*	*p*	η_p^2
Child quality of life[a]									
Cognitive difficulties[b] (*n* = 28)	49.93	22.56	53.40	25.47	52.75	24.78	0.415	.664	.03
Pain and hurt (*n* = 43)	72.48	24.50	72.87	26.11	68.22	26.18	1.104	.341	.05
Movement and balance (*n* = 43)	69.77	28.41	70.93	30.18	69.38	29.87	0.142	.868	.01
Procedural anxiety (*n* = 43)	41.28	32.73	43.60	33.47	46.71	38.41	0.485	.619	.02
Nausea (*n* = 43)	64.30	27.94	68.95	28.76	72.09	27.67	2.83	.071	.12
Worry (*n* = 43)	67.64	30.28	56.20	30.65	64.73	31.54	2.612	.086	.11
Caregiver quality of life (*n* = 42)[a]	82.55	22.84	85.63	24.57	88.21	25.27	2.996	.061	.13
Burden (*n* = 43)	14.88	5.25	16.58	6.34	17.58	7.19	6.482	.004**	.24
Disruptiveness (*n* = 42)	11.36	4.66	12.05	4.98	13.64	4.93	6.872	.003**	.26
Positive adaptation (*n* = 42)	18.21	4.64	18.55	5.32	19.07	4.88	1.120	.336	.05
Financial concerns (*n* = 42)	7.81	3.90	7.860	3.80	8.50	3.66	2.574	.089	.11
Family functioning (*n* = 36)[c]	1.66	0.50	–	–	1.69	0.55	−0.412	.683	.00

Abbreviations: M, mean; SD, standard deviation.
**$p < .01$.
[a]Score direction: higher scores = better quality of life.
[b]Items apply only to children aged 5 years and older.
[c]Score direction: higher scores = more problematic functioning.

There was a main effect of tumour risk for levels of reported nausea, F (1, 41) = 15.75, $p < .001$, $\eta_p^2 = .28$, with the low-risk tumour group reporting better experiences at each timepoint. There was also a main effect of treatment, F (1, 41) = 45.71, $p < .001$, $\eta_p^2 = .53$, with those having received any chemotherapy and/or radiation reporting more concerning scores at each timepoint.

Worry only significantly differed by treatment received, F (1, 41) = 6.525, $p = .014$, $\eta_p^2 = .14$, with those who had received any chemotherapy and/or radiation perceived as being more worried by their parent/carers at each timepoint, with a notable increase in worry at Time 2.

2.4 | Caregiver quality of life

Overall caregiver quality of life differed by the treatment the child received, F (1, 40) = 6.503, $p = .015$, $\eta_p^2 = .14$, where those whose child received any chemotherapy and/or radiation reported lower quality of life at each timepoint compared with surgery only or other treatment. There was also a main effect for age at diagnosis, F (1, 40) = 5.030, $p = .031$, $\eta_p^2 = .11$, where those whose child was diagnosed aged 4 years or younger reported lower quality of life at each timepoint. A further main effect was observed for household income, F (1, 36) = 5.161, $p = .029$, $\eta_p^2 = .13$, with those who had a lower income reporting worse quality of life at each timepoint.

Findings from the analyses of the caregiver quality of life subscales (burden, disruptiveness, positive adaptation, financial concerns) are presented in Supporting Information, Supplementary File 1.

2.5 | Family functioning

There was significant interaction between time and tumour risk, Wilks' Lamba = 0.891, F (1, 34) = 4.564, $p = .049$, $\eta_p^2 = .11$ (Figure 2). From Time 1 (M = 1.64, SD = 0.47) to Time 2 (M = 1.84, SD = 0.64), family functioning became more problematic for those with a child who had a low-risk tumour, while those with a high-risk tumour had an improvement in family functioning from Time 1 (M = 1.68, SD = 0.55) to Time 2 (M = 1.54, SD = 0.55).

Family functioning did not statistically differ by treatment received, age at diagnosis, location from hospital or household income.

2.6 | Analysis of relationships between outcome variables

2.6.1 | Does child quality of life at Time 1 predict caregiver quality of life at Time 3? (RQ 2)

Four child quality of life scales significantly correlated with caregiver quality of life at Time 3, presented in descending order of correlation coefficient: cognitive difficulties ($r = .63$, $n = 33$, $p < .001$), pain and

TABLE 4 Means and standard deviations for each timepoint for child and caregiver quality of life where significant effects were observed.

	Time 1		Time 2		Time 3	
Variable	***M***	**SD**	***M***	**SD**	***M***	**SD**
Child quality of life[a]						
Cognitive difficulties × household income (interaction effect; $n = 24$)						
<$70,000	37.09	20.87	25.89	14.81	30.61	23.53
≥$70,000	52.44	22.76	65.55	21.22	61.34	23.07
Pain and hurt × treatment ($n = 43$)						
Surgery only or other	82.58	19.23	82.20	26.39	77.65	24.31
Any chemotherapy and/or radiation	61.90	25.35	63.10	22.45	58.33	24.86
Pain and hurt × income ($n = 38$)						
<$70,000	60.61	27.91	56.82	30.00	53.03	24.52
≥$70,000	75.00	22.29	79.01	22.81	74.07	24.28
Movement and balance × treatment ($n = 43$)						
Surgery only or other	82.95	17.34	84.09	21.35	83.33	21.36
Any chemotherapy and/or radiation	55.95	31.42	57.14	32.31	54.76	30.91
Nausea × tumour risk ($n = 43$)						
Low	78.70	17.40	81.52	21.92	82.83	24.81
High	47.75	28.90	59.75	26.08	59.75	26.08
Nausea × treatment ($n = 43$)						
Surgery only or other	82.95	16.01	87.27	18.04	89.55	18.19
Any chemotherapy and/or radiation	44.76	24.21	49.76	25.27	53.81	23.67
Worry × treatment ($n = 43$)						
Surgery only or other	72.73	22.45	70.08	21.92	71.21	25.42
Any chemotherapy and/or radiation	62.30	36.57	41.67	32.17	57.94	36.27
Caregiver quality of life[a]						
Treatment ($n = 42$)						
Surgery only or other	88.70	21.51	93.33	20.65	98.40	21.78
Any chemotherapy and/or radiation	75.78	22.85	77.16	26.22	77	24.54
Age at diagnosis ($n = 42$)						
4 years and under	71.95	21.22	76.93	24.20	73.83	26.08
5 years plus	87.30	22.26	89.53	24.13	94.65	22.48
Household income ($n = 38$)						
<$70,000	69.61	26.58	70.19	28.89	73.57	27.01
≥$70,000	84.93	19.88	90.03	21.22	91.41	23.70

Notes: All variables had a main effect for the sociodemographic/clinical variable of interest on the outcome variable of interest only.
Abbreviations: M, mean; SD, standard deviation.
[a]Score direction: higher scores = better quality of life.

hurt ($r = .42$, $n = 51$, $p = .002$), nausea ($r = .36$, $n = 51$, $p = .009$) and movement and balance ($r = .29$, $n = 51$, $p = .037$). Two potential covariates also each significantly correlated with caregiver quality of life at Time 3: household income ($r = .34$, $n = 55$, $p = .010$) and treatment type ($r = -.32$, $n = 66$, $p = .010$).

A multivariate regression analysis was not appropriate with six predictors and a small sample size ($n = 32$) due to the risk of model overload[26] (RQ 2a).

2.6.2 | Is caregiver quality of life associated with family functioning at Time 3? (RQ 3)

There was a moderate, negative correlation between family functioning and caregiver quality of life at Time 3, $r = -.45$, $n = 54$, $p < .001$, with higher scores on quality of life associated with lower levels of problematic family functioning. Three caregiver quality of life subscales correlated with family functioning: positive adaptation ($r = -.51$,

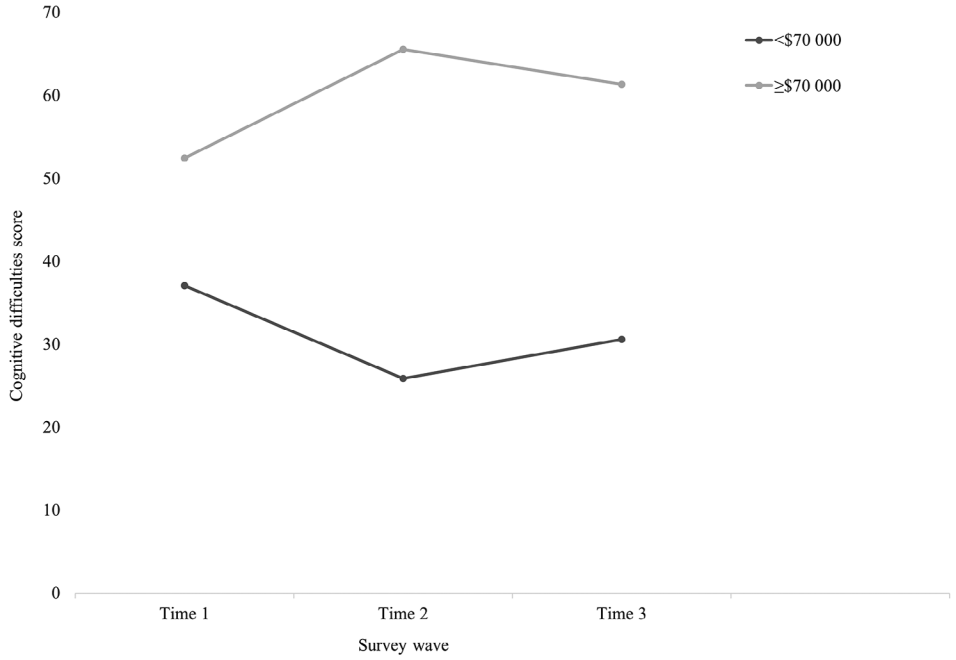

FIGURE 1 Interaction between time and household income for cognitive difficulties (child quality of life).

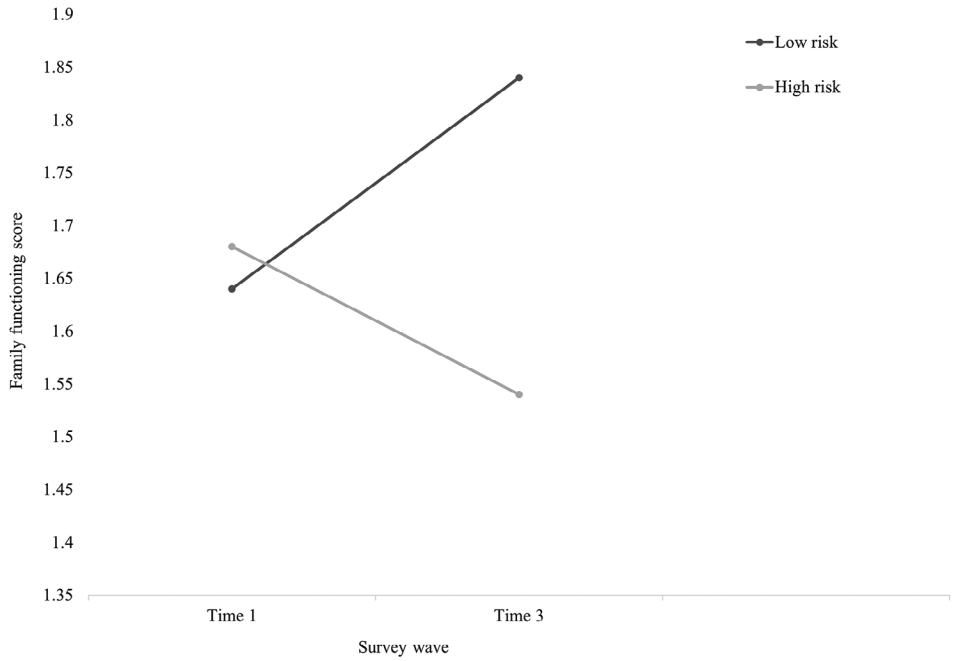

FIGURE 2 Interaction between time and tumour risk for family functioning.

$n = 54$, $p < .001$), disruptiveness ($r = -.29$, $n = 54$, $p = .034$) and burden ($r = -.28$, $n = 54$, $p = .041$). Tumour risk, treatment type, age at diagnosis, household income and distance located from the hospital did not correlate with family functioning at Time 3.

When all three variables with significant univariate associations (burden, disruptiveness, positive adaptation) were entered into a multivariate model (RQ 3a), the total variance explained was 27.6%, $F(3, 50) = 6.35$, $p < .001$. Positive adaptation was the only statistically significant predictor (*beta* = −.66, $p < .005$).

3 | DISCUSSION

To the best of our knowledge, this is the first longitudinal analysis of child (proxy reported) and caregiver quality of life in the first 12 months after diagnosis of a paediatric brain tumour. Child quality of life did not improve in the first 12 months. The 12-month scores in our sample were considerably worse than those recently reported by parents on the same PedsQL scale for dates that also included the Covid-19 pandemic.[27,28] Mean cognitive difficulties, for example, was

70.3 in a Canadian study[27] (83% still on treatment) and 72.18 in a Chinese study[28] (median 35 months since diagnosis), compared with 52.75 in our sample at 12 months post-diagnosis. Cognitive difficulties did not differ by tumour grade, potentially reflecting the immense impact low grade and non-malignant tumours can also have for children and their families.[9,29] Nor did they differ for treatment type; longer follow-up may be needed to detect such differences, though some research findings suggest that impacts on health-related quality of life for paediatric brain tumour survivors are independent of treatment period.[30–33] Parents with a lower household income reported worse cognitive difficulties and pain and hurt at each timepoint for their child, consistent with several studies to have evidenced children diagnosed with cancer from households with low-income experience higher symptom burden and lower quality of life.[34–37] These associations are underpinned by a complex constellation of biopsychosocial variables at the individual, familial, community and societal levels.[34–37] All families in our study received comprehensive medical and nursing care, including access to pain relief. The study hospital provides a range of social work, welfare and psychology services to children and their families. There are also a range of community services and charities in Australia that provide psychosocial support. Families' awareness of these and access to them can vary greatly,[13] particularly since the Covid-19 pandemic commenced.[22,23]

Overall caregiver quality of life also did not improve, in contrast to the broader childhood cancer research that describes distress as reducing to baseline levels about 6 months after the initial shock of diagnosis.[5] It is difficult, however, to determine the evidence base for this frequently stated claim, and it is at odds with long-term studies such as those on the lifetime prevalence of post-traumatic stress disorder for parents and children at 27–54%.[38] Quality of life was lower across all three timepoints for those with a child who had any chemotherapy and/or radiation, a child aged less than 4 years, and/or a lower household income. All three of these variables are associated with increased caregiver distress in early and later years post-diagnosis.[11,39,40] Our findings suggest that having a child who has significant cognitive difficulties early after diagnosis takes a considerable toll on caregiver's quality of life in the first 12 months. These children likely require complex care that impacts caregiver quality of life, though studies suggest that family-level factors (e.g., cohesiveness, good communication) can moderate this.[41,42] This is consistent with our finding that the ability for caregivers to 'positively adapt' to the experience of childhood brain tumour was strongly supported by good family functioning at 12 months. Of note, we found that family functioning improved over time for those diagnosed with a high-grade tumour, in comparison with the wider literature that reports more intense treatments (typically required for higher tumour grades) as being as risk factor for more maladaptive family functioning.[9] This may reflect that these families received more formal and informal psychosocial support—at least within the first 12 months post-diagnosis—due to the more recognisable risk of their child's condition.[43]

Our study is limited in that we were unable to compare respondents with non-respondents due to how data are routinely collected by hospital administration. Our findings are likely influenced by the stress and uncertainty of living in the Covid-19 pandemic; we did not have a historical control group to assess this, but sensitivity analyses comparing the outcome measures across three different time periods with varying pandemic-related impacts on healthcare did not yield significant differences. Our sample size did not enable further multivariate analyses to address RQ 2a and potentially reduced our statistical power. However, given the size of the study population—there are 172 cancer cases per million children per year in Australia[3]—it is a considerable sample. It was not possible to categorise treatment status due to the instability of brain tumour and treatment in this population of recently diagnosed children. We also had no knowledge of parents'/carers' quality of life prior to their child's cancer diagnosis. The child's quality of life was proxy reported by parents/carers; this has been evidenced as a reliable measure for the PedsQL Brain Tumour Module.[33] It is, however, possible that this adds bias to our study where parents/carers also completed their own quality of life measures.

While there is an expectation that most families are resilient and cope well with the challenges of childhood cancer,[5] brain tumour has been flagged as a predictor of adverse psychosocial outcomes for the child and their family.[44,45] The findings from the current paper and our broader study suggest that these families would benefit from additional support.[12,13] The Paediatric Psychosocial Preventative Health Model is an established model to address the psychosocial care of families in childhood cancer, with over half of all families typically classified in the 'universal' risk category[6]: 'these are normally functioning families experiencing distress related to their medical experiences.…These families are the least likely to receive psychosocial assessment or treatment, as they are assumed to not qualify for such care…or because they do not ask for or expect such care' (p. 386).[46] This is a complex space with challenges such as limited associated resources available,[47] unconscious biases that impact perceptions of families' needs[6] and a lack of post-treatment survivorship psychosocial care models.[48,49] Our findings suggest the following factors indicate a need for increased early psychosocial support to reduce later adversity when families are less likely to be in contact with services: cognitive difficulties for the child (at any timepoint from diagnosis), less than 4 years of age at diagnosis, the use of any chemotherapy and/or radiation, and low household income.

Interventions that address caregiver quality of life, in particular positive adaptation, and support family functioning from diagnosis may improve long-term psychosocial outcomes for the child and their family.[9] Parents/carers in this study have previously identified the need for accessible emotional support for themselves.[13] There are logistical, legal and ethical challenges to providing psychosocial care to adults in a paediatric setting.[50] While there are several community organisations in Australia who offer such support (e.g., free counselling and financial assistance through RedKite: redkite.org.au; paid family holiday through Brainchild: brainchild.org.au), parents/carers can find it difficult to locate and access such care themselves at an immensely challenging time.[4,13] Nurse navigation and co-ordination can assist with this,[51] and there are several hospital-adjacent 'caring for the

carer' interventions in the adult cancer space that could be adapted to this population.[52,53]

4 | CONCLUSIONS

The findings of the current paper suggest the following factors indicate a need for increased early psychosocial support to reduce later adversity: cognitive difficulties for the child (at any timepoint from diagnosis), less than 4 years of age at diagnosis, the use of any chemotherapy and/or radiation and low household income. We are continuing to follow these families until 24 months post-diagnosis to examine longitudinal effects on quality of life, family functioning and economic impact.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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