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Quality of life and family functioning soon after paediatric brain tumour diagnosis: A cross-sectional observational study

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ABSTRACT

Purpose: There is scant scholarly exploration of quality of life in families with a child who has a brain tumour early after diagnosis, despite this being a pivotal point in their illness trajectory. We aimed to describe quality of life in children and their parents, and family functioning, within six months of diagnosis; and to examine if this differed for various subpopulations.

Method: This is a cross-sectional analysis of baseline data of an ongoing longitudinal survey. Parents/carers of a child who had a diagnosis of a malignant or non-malignant brain tumour and were receiving care at the Queensland Children's Hospital were invited to complete an electronic survey. Univariate analyses were conducted with potential covariates and each dependent variable (child quality of life, caregiver quality of life, family functioning). Potential relationships between the outcome variables were explored through Pearson's correlation coefficient.

Results: Seventy-nine diverse families completed the survey between August 2020 and September 2022. Caregiver quality of life did not differ by the child's tumour risk grade. It was lowest for those with a child who had undergone chemotherapy and/or radiation compared to surgery only, and for those with a child who had been diagnosed 6 months prior to survey completion compared to more recent diagnoses. A third of families reported problematic family functioning. Lower levels of problematic family functioning were associated with higher caregiver quality of life ($r = -.49$, $p < .001$).

Conclusions: Our findings suggest caregivers need greater psychosocial support early after diagnosis, and supports the need for family-centred care that fosters communication and cohesiveness.

1. Introduction

Brain tumour is the most common and deadliest solid tumour for children worldwide (Steliarova-Foucher et al., 2017; Aldape et al., 2019). Approximately 25% of children diagnosed with a malignant brain tumour in high income countries will not survive (Girardi et al., 2019). When a child does survive, they often do so with life-long, complex additional conditions (e.g., memory deficits, seizures, impaired mobility) from having had a tumour and treatment at a pivotal point in their physical and cognitive development (Turner et al., 2009). This can inhibit completion of tertiary education, gaining employment, and having intimate relationships (Schulte et al., 2019). Subsequently, parents and/or carers—most often mothers—become long-term caregivers covering a complex array of duties with little support (Young et al., 2021; Nicklin et al., 2019; Roser et al., 2019).

Childhood cancer is an extremely challenging and stressful experience for the child and their family (Kazak et al., 2015). Research from childhood cancer more broadly suggests distress is highest at diagnosis,

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returning to baseline levels by six months; however, multiple studies report 10–30% of families experience long-term adverse psychosocial outcomes (Kazak et al., 2015; Schulte et al., 2017; Shah et al., 2015). Having had a brain tumour in childhood has consistently been associated with lower QoL later in life, with risk factors including infratentorial tumour, having had radiation therapy, and experiencing behavioural problems (Bell et al., 2018). A recent study in England found QoL for caregivers of youth with a brain tumour to be considerably low five years post-treatment, scoring on average below the second quartile (Nicklin et al., 2022). There is scant scholarly research exploring caregiver and child quality of life (QoL) in childhood brain tumour early after diagnosis and during active treatment. It is essential to investigate this to ensure appropriate services and resources are available for families at the time when distress is thought to be highest (Kazak et al., 2015) and when they have the most contact with clinical services (Tonorezos et al., 2018).

Moscato et al. (2022) have evidenced the protective effects of adaptive family functioning—cohesiveness, effective communication, lower conflict—against long-term adverse psychosocial outcomes for paediatric brain tumour survivors. Socioeconomic factors, such as household income and social support system, contribute to families' overall adjustment, functioning, and wellbeing (Kazak et al., 2015; Moscato et al., 2022; Kazak and Noll, 2015). Poor family functioning has been associated with poorer QoL for both children and parents (Bell et al., 2018; Moscato et al., 2022). Quast et al. (2018), for example, reported that low family functioning (child-rated) at 1-month post-treatment predicted poor QoL nine months later.

As with QoL, few studies have examined family functioning early after diagnosis (Moscato et al., 2022), despite this being a pivotal point in families' experiences (Young et al., 2021; Young et al., 2023). Such investigations are essential to informing clinical practice, particularly for paediatric oncology nurses who are a consistent presence in the hospital for families, and who often oversee their care navigation and coordination (Paediatric Integrated Cancer Service, 2019; Hudson et al., 2019). Nurses must be able to identify and support (including referring appropriately) the psychosocial needs of each family member from diagnosis onward (Challinor, 2022; Wiener et al., 2015). We thus aimed to.

1. Describe QoL in children and their parents, and general family functioning, within six months of diagnosis of a brain tumour for the child.
2. Examine if and how these differed for different sub-populations (e.g., low/high risk tumour).

2. Methods

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

2.1. Study design and setting

This cross-sectional analysis is embedded in a larger project that includes a longitudinal survey and interviews. The current paper considers the first survey only. Participants were recruited from the Queensland Children's Hospital (QCH), which is a tertiary public hospital located in the city of Brisbane in the state of Queensland, Australia. Despite the state's vast geographical dispersion, covering an area of 1.853 million square kilometres, all children (0–14 years) and many adolescents (15–18 years) diagnosed with cancer—approximately 280 per year—receive centralised oncology care through QCH.

2.2. Sample and recruitment

Parents and carers of a child (aged 18 years or under) diagnosed with a malignant or non-malignant brain tumour within the last 6 months, and who were receiving care at QCH, were invited to complete the survey. To be eligible, carers must have been at least 18 years old and able to read and understand English.

Our clinical research nurse (Author B) identified potential families at the weekly Solid Tumour 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 tell them about the study and followed established recruitment principles, giving families time to make decisions about their involvement (Bradford et al., 2021). If interested, participants provided their written informed consent prior to completing the first survey—delivered through REDCap (Harris et al., 2019)—on our tablet device or on their own devices through a link emailed to them. Data analysed for the present paper were collected between August 2020 and September 2022; this timeframe reflects Covid-19 related restrictions to hospital-based research and the need to wait for new diagnoses that are relatively uncommon at the population level (Australian Institute of Health and Welfare, 2020).

2.3. Measures and data management

To reduce participant burden, where available we collected demographic and clinical information from hospital records. We categorised each child's diagnosis into low or high grade based upon the WHO classification (Louis et al., 2021).

2.3.1. Caregiver QoL

Caregivers completed the 35 item Caregiver Quality of Life Index-Cancer (CQOLC) scale (Weitzner et al., 1999), with one item (*Satisfaction with sexual functioning*) omitted due to concerns for this population expressed by staff at the research hospital. To be comparable to previous research, we replaced this value with the scale mean for each participant. The CQOLC included four pre-validated subscales: burden, disruptiveness, positive adaption, and financial concern. Total and subscales scores were calculated as instructed in Duan et al. (2015). The highest total score was 140 with higher scores indicating better QoL. In this study, internal consistency was 0.92 for the total scale (0.65–0.89 for the subscales).

2.3.2. Child QoL

Caregivers completed the Brain tumour Module Quality of Life Index (PedsQL – Brain tumour Module) on behalf of their child (Mapi Research Trust and Varni, 2023). This device 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, and worry. Sub-scales were scored as prescribed in Mapi Research Trust and Varni (2023). Each subscale had a total highest score of 100, with higher scores indicating less severe problems. In this study, internal consistency was high (0.89–0.93) for each subscale.

2.3.3. Family functioning

Family functioning was measured by the 12 item McMaster Family Assessment Device General Functioning sub-scale (FAD-GFS) and scored as outlined in Epstein et al. (1983). An example item is: "We cannot talk to each other about the sadness we feel." 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. In this study, internal consistency was 0.91.

2.4. Analyses

Descriptive analyses to describe the overall sample demographics and mean scale scores were conducted. Differences across independent variables (listed in Table 1) for each outcome variable/s (and subscales in the case of CQOLC) were conducted with an independent samples two-tailed *t*-test for binary variables, and ANOVA (with post hoc comparisons by Turkey's test) for variables with more than two levels.

Table 1
Participant demographics and clinical details.

Variable	Sample characteristics N = 79 n (%)
Tumour classification	
Low-grade brain tumour	35 (44)
High-grade brain tumour	44 (55)
Tumour type	
Embryonal	19 (24)
Astrocytoma	21 (27)
Brain stem glioma	6 (8)
Ependymoma	2 (3)
Optic nerve glioma	1 (1)
Choroid plexus	2 (3)
Craniopharyngioma and pituitary	6 (8)
Dysembryoplastic neuroepithelial	3 (4)
Germ cell	4 (5)
Pineal region	1 (1)
Retinoblastoma	8 (1)
Other	6 (8)
Treatments received[a]	
Observation only	4 (5)
Surgery	68 (86)
Chemotherapy	40 (51)
Radiation	34 (43)
Time since diagnosis	
6 weeks	25 (32)
3 months	40 (51)
6 months	14 (17)
Age at diagnosis, years – median (min-max)	6.9 (0.25–17)
Child Sex	
Male	51 (65)
Female	28 (35)
Caregiver	
Mother	63 (80)
Father	11 (14)
Other – aunt, grandmother	4 (5)
Missing	1 (1)
Parenting make-up	
Single parent	8 (10)
Parents coupled	70 (89)
Missing	1 (1)
Sibling make-up	
Only child	8 (1)
One or more siblings	60 (76)
Missing	11 (14)
Indigenous Australian[b]	
Yes	6 (8)
No	72 (91)
Missing	1 (1)
Location from treating hospital, kilometres – median (min-max)	53 (4–3426)
Annual household income ($AUD)	
< 70 000	18 (23)
> 71 000	27 (34)
Prefer not to say	16 (20)
Missing	18 (23)

[a] Categories collapsed for analysis to: Chemotherapy and/or radiotherapy, surgery only, other.
[b] At least one immediate family member identified as Indigenous Australian.

Potential relationships between the outcome variables were explored through Pearson's correlation coefficient. Preliminary analyses were conducted to ensure that data met all assumptions for each reported analysis. Missing data was managed as dictated in each scale's scoring instructions (Duan et al., 2015; Mapi Research Trust and Varni, 2023; Epstein et al., 1983); pairwise exclusion of cases was applied for socio-demographic data. Statistical significance was set at a p-value of .05 and confidence intervals calculated at a confidence level of 95%.

3. Results

Our sample consisted of 79 caregivers representing distinct families; their sociodemographic and clinical characteristics are presented in Table 1. Twenty-three additional surveys were excluded from analysis (had not completed baseline survey, n = 17; duplicate survey for same family, n = 1; diagnosis >6 months previously, n = 3), and a further 32 families were approached but declined to participate.

Our findings are likely influenced by the stress and uncertainty of living in the Covid-19 pandemic. We conducted a sensitivity analysis comparing the three outcome measures between those completing the survey before and after the strictest Covid-19 state government regulations were in place (ending December 2021; Queensland Government, 2022) during the study period; and found no significant differences.

3.1. Caregiver QoL

The overall mean caregiver QoL score was 83.48 (SD = 23.02).

Caregiver QoL significantly differed across treatment groups, with post hoc comparisons revealing lower QoL for those with a child who had received chemotherapy and/or radiation compared to surgery only (Table 2). This was also the case for the burden, disruptiveness, and financial concern subscales (Table 2).

Caregiver QoL also significantly differed by time since the child's diagnosis. Those who had been diagnosed 6 months prior reported lower QoL compared to those who had been diagnosed 3 months prior (Table 2). We report similar findings for the burden and financial concern subscales (Table 2).

Financial concerns significantly differed across household incomes, $F(2, 58) = 5.53$, $p = .006$, $\eta^2 = 0.16$. Those who earned AU$70 000 or less (N = 18) held significantly higher concerns (M = 5.06 SD = 3.54) than did those who earned more (N = 27, M = 8.52, SD = 3.47) or who preferred not to disclose their income (N = 16, M = 8.25, SD = 3.92).

3.2. Child QoL

Movement and balance were rated worse by parents for children defined as high risk (N = 44, M = 63.44, SD = 28.31) compared to low risk (N = 35, M = 76.66, SD = 26.72), $t(77) = 2.11$, $p = .038$, $\eta^2 = 0.05$. This was also the case for nausea (high risk: N = 44, M = 49.09, SD = 30.12; low risk: N = 35, M = 80.86, SD = 17.71), $t(77) = 5.52$, $p < .001$, $\eta^2 = 0.28$. However, procedural anxiety (M = 36.18, SD = 31.77), worry (M = 62.99, SD = 31.83), pain and hurt (M = 69.51, SD = 26.21), and cognitive difficulties (M = 46.37, SD = 20.79) were rated as being equally problematic for all children, regardless of tumour risk.

Three scales differed across treatment groups: pain and hurt, movement and balance, and nausea, with each being most problematic for those children who had received chemotherapy and/or radiation (Table 3). 'Pain and hurt' and 'movement and balance' were also found to differ across diagnosis times, with scores being lowest in those who had been diagnosed 6 months prior to survey completion (Table 3).

Fathers (N = 11) rated their child as having higher procedural anxiety (M = 15.91, SD = 23.99) than did mothers (N = 67, M = 39.93, SD = 31.80), $t(76) = 2.93$, $p = .010$, $\eta^2 = 0.10$. Parents who did not have another child (N = 8) rated their child's movement and balance as being poorer (M = 46.88, SD = 36.17) than those with one or more additional children (N = 60, M = 71.53, SD = 26.19), $t(66) = -2.39$, $p = .020$, $\eta^2 = 0.08$.

3.3. Family functioning

The mean family functioning score for the sample was 1.75 (SD = 0.48), with 25 (32%) families indicating problematic functioning. Families who had at least one member identifying as Indigenous Australian (N = 5, M = 1.20, SD = 0.28) reported better family functioning than did those who did not (N = 56, M = 1.78, SD = 0.47), $t(59) = -2.72$, $p = .009$, $\eta 2 = 0.11$.

Table 2
Caregiver QoL by child's treatment and time since diagnosis.

Group	Total score			Burden		Disruptiveness		Financial concern	
	N	M	SD	M	SD	M	SD	M	SD
Treatment/s child had received: F (2, 76) = 6.692, p = .002, η^2 = 0.15[a]									
				F [2, 76] = 5.747, p = .005, η^2 = 0.15		F [2, 76] = 6.835, p = .002, η^2 = 0.15		F [2, 76] = 9.134, p < .001, η^2 = 0.19	
Chemotherapy and/or radiation	44	75.62	21.15	13.32	5.51	9.91	4.81	6.11	3.82
Surgery only	27	94.00	21.81	17.41	5.39	13.96	4.39	9.56	2.79
Other	8	91.21	22.45	17.75	5.15	13.25	4.80	9.25	3.69
Time since diagnosis: F (2, 76) = 3.88, p = .025, η^2 = 0.9[b]									
				F [2, 76] = 3.352, p = .040, η^2 = 0.08		N.S.		F [2, 76] = 5.593, p = .005, η^2 = 0.13	
6 weeks	25	82.13	23.39	14.76	6.57	–	–	7.40	3.45
3 months	40	89.04	21.12	16.50	4.77	–	–	8.68	3.56
6 months	14	70.00	23.15	12.07	5.88	–	–	4.93	4.08

N.S. = not significant.
[a] In all analyses, post hoc comparisons revealed a statistically significant difference between 'chemotherapy and/or radiation' and 'surgery only' groups only.
[b] In all analyses, post hoc comparisons revealed a significant difference between the '3 months' and '6 months' groups only.

Table 3
Child QoL by child's treatment and time since diagnosis.

Group	Pain and hurt			Movement and balance		Nausea	
	N	M	SD	M	SD	M	SD
Treatment/s child had received[a]							
	F (2, 76) = 10.902, p < .001, η^2 = 0.22			F (2, 76) = 10.002, p < .001, η^2 = 0.21		F (2, 76) = 26.997, p < .001, η^2 = 0.42	
Chemotherapy and/or radiation	44	59.85	26.25	57.95	30.60	46.14	27.66
Surgery only	27	86.42	17.62	82.41	16.72	84.26	15.85
Other	8	65.63	23.75	87.5	15.43	85.63	12.66
Time since diagnosis[b]							
	F (2, 76) = 8.875, p < .001, η^2 = .19			F (2, 76) = 3.781, p = .027, η^2 = .09		N.S.	
6 weeks	25	69.33	24.14	63.67	27.10	–	–
3 months	40	77.71	23.60	77.29	26.62	–	–
6 months	14	46.43	24.40	56.55	29.45	–	–

N.S. = not significant.
[a] Pain and hurt, movement and balance: post hoc analyses revealed significant differences between the 'chemotherapy and/or radiation' and 'surgery only' groups only; nausea: post hoc analyses revealed significant differences between the 'chemotherapy and/or radiation,' and (1) 'surgery only' and (2) 'other' groups.
[b] Pain and hurt: post hoc analyses revealed a significant differences between the '3 months' and '6 months' groups, and the '6 weeks' and '6 months' groups only; movement and balance: post hoc analyses revealed significant differences between the '3 months' and '6 months' groups only.

3.4. Associations between outcome variables

There was a moderate negative correlation between family functioning and caregiver QoL, r = -.49, n = 62, p < .001, with low levels of problematic family functioning associated with higher levels of caregiver QoL. All caregiver QoL subscales significantly correlated with family functioning (Table 4). All child QoL subscales significantly correlated with caregiver QoL, except for procedural anxiety (Table 4). No child QoL subscale significantly correlated with family functioning.

Table 4
Significant relationships between outcome measures.

Caregiver QoL subscales	Family functioning N = 62
Burden	−.38**
Disruptiveness	−.32*
Positive adaption	−.42**
Financial concerns	−.32*
Child QoL subscales	**Caregiver QoL N = 79**
Cognitive difficulties[a]	.43**
Pain and hurt	.48**
Movement and balance	.29*
Procedural anxiety	.00
Nausea	.32**
Worry	.33**

**Correlation significant at the 0.01 level (2-tailed).
*Correlation significant at the 0.05 level (2-tailed).
[a] N = 51 due to the scale only being applicable to children aged 5 years and above.

4. Discussion

4.1. Summary of findings

This study is the first to report caregiver QoL, child QoL, and family functioning in the first six months after diagnosis of a paediatric brain tumour. Caregiver QoL was lowest for those with a child who had undergone chemotherapy and/or radiation, and for those with a child who had been diagnosed 6 months prior to survey completion. Procedural anxiety, worry, pain and hurt, and cognitive difficulties were equally problematic for children regardless of their tumour risk grade. A third of all families reported problematic family functioning. Lower levels of problematic family functioning were associated with higher caregiver QoL. Children's QoL—except for procedural anxiety—positively correlated with caregiver QoL. There was no correlation detected between child QoL and family functioning.

4.2. Comparison to previous research

Overall, families in our sample appear to be struggling more than what has previously been reported (Nicklin et al., 2022; Lim et al., 2017; Palmer et al., 2007; Moscato et al., 2022). However, the following comparison studies have all been conducted prior to the Covid-19 pandemic making it difficult to discern if our more concerning findings reflect this, or specific care or location factors. Our mean caregiver QoL score (83.48) was higher than that reported in Nicklin et al. (2022) in a smaller sample of caregivers to young adult brain tumour survivors

in England more than 5 years post diagnosis (M = 63.19), but considerably lower than that reported for carers of adult family members with cancer at similar and later timepoints (Canada: 98.8; USA: 95.3; UK: 88.9; Lim et al., 2017). Previous childhood cancer research suggests that caregiver distress—including various QoL measures—reduces by 6 months post diagnosis (Kazak et al., 2015). In our sample, however, QoL was lowest for those completing the survey at 6 months post diagnosis, suggesting a possible difference for caregivers of a child with a brain tumour compared to other childhood cancers. Our child QoL scale mean scores were lower than that reported by 99 families of paediatric brain tumour patients in Los Angeles, America, in Palmer et al. (2007), most notably on the cognitive difficulty (46.37 versus 68.36) and procedural anxiety (36.18 versus 61.82) scales.

Our mean family functioning score (1.75) was more problematic than the five studies of parents using the same measurement device reviewed in Moscato et al. (2022; FAD-GFS: 1.55–171). However, these authors suggest early post-diagnosis is associated with family dysfunction that, for most, will resolve over time; and that functioning during the transition off treatment may instead be more predictive of long-term adaption.

In the broader childhood cancer literature, caregiver QoL is consistently associated with child QoL (López León, Carreño Moreno and Arias-Rojas, 2021; Bakula et al., 2020), including in Barrera et al. (2022) where measurements were also taken within 6 months of diagnosis. The limited literature specific to brain tumour suggests a similar association that may be mediated by caregiver burden (Litzelman et al., 2011). Caregiver QoL was also associated with family functioning. Mother-caregivers, who shoulder much childhood cancer caregiving (Young et al., 2021; Nicklin et al., 2019; Roser et al., 2019), have described the importance of effective communication and cohesiveness within both the family and parental relationship to reduce burden and feel supported in their caring (Da Silva et al., 2010; Young et al., 2021). In paediatric brain tumour survivors, positive family functioning is known to be protective of survivor QoL (Moscato et al., 2022; Moscato et al., 2023; Bell et al., 2018); however, in our study of those in the early post-diagnosis phase and of a younger age, we found no such association.

4.3. Study limitations

There are several limitations to the generalisability of our findings. We did not have a 'healthy' control group, nor a historical pre-Covid-19 pandemic comparison. We were unable to compare respondents to non-respondents due to how data is routinely collected by hospital administration. The CQOL scale, while commonly used in paediatric research (Tanco et al., 2017), has not been validated in this population. The child's quality of life was proxy reported by parents; this has been evidenced as valid in the PedsQL brain tumour module used (Palmer et al., 2007). Male caregivers are underrepresented in our study, a known phenomenon in childhood cancer research Davies et al. (2023). Our sample size—a considerable one considering there are ~120 new malignant paediatric brain tumour diagnoses each year in Australia (Australian Institute of Health and Welfare, 2020)—did not meet the requirements for additional multivariate analyses, such as structural equation modelling, to inform a model of how the outcome measures work concurrently. Nevertheless, our findings contribute much needed literature on QoL and family functioning in the early stages of the paediatric brain tumour experience, using a sample of clinical and sociodemographic diverse families.

4.4. Clinical implications

Our findings suggest paediatric oncology nurses support the provision of psychosocial support to families who have a child diagnosed with a brain tumour from diagnosis and beyond. Nurses should remain vigilant about the need for such support even when several months have passed since diagnosis in this population; this in contrast to models from general childhood cancer research that suggest distress is highest at diagnosis and returns to baseline levels by six months (Kazak et al., 2015). All families—regardless of tumour grade—may need such support, though our findings suggest that the experience of receiving chemotherapy and/or radiation does bring additional quality of life concerns for parents/carers. Often care is structured around the diagnosed child due to being in a paediatric setting and associated funding structures (Jones et al., 2018); however, our findings, along with several others (see, for example, (Moscato et al., 2022; Bakula et al., 2020) demonstrate the need to consider the wellbeing of parents/carers and functioning of the family unit as key factors associated with the child's wellbeing throughout treatment and into long term survivorship. Paediatric oncology nurses are well positioned to be advocates for, and providers of, care that recognises the impact of childhood brain tumour on the whole family (Tedford and Price, 2011; MacKay and Gregory, 2011).

5. Conclusion

We are continuing to follow these families for 24 months post diagnosis to examine longitudinal effects on quality of life, family functioning, and economic impact. The presently reported baseline findings, however, support the need for psychosocial care targeted at caregivers early after a diagnosis of their child's brain tumour. This is recommended within the Standards for Psychosocial Care for Children with Cancer and their Families (Wiener et al., 2015), and has been specifically requested by caregivers of children with a paediatric brain tumour in the study hospital (see Young et al., 2023). We are currently working to co-design a hospital-adjacent intervention that works with existing pathways to support the psychosocial wellbeing of caregivers and facilitates adaptive family functioning.

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CRediT authorship contribution statement

Kate Young: Data curation, Formal analysis, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing. **Christine Cashion:** Data curation, Investigation, Project administration, Validation. **Stuart Ekberg:** Conceptualization, Funding acquisition, Project administration, Writing – review & editing. **Timothy Hassall:** Conceptualization, Funding acquisition, Project administration, Resources, Validation, Writing – review & editing. **Natalie Bradford:** Conceptualization, Funding acquisition, Methodology, Project administration, Resources, Supervision, Validation, Writing – review & editing.

Declaration of competing interest

The authors have no competing interests to declare.

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