Title: Long-term health-related quality of life in young childhood cancer survivors and their parents

Brief title: Long-term HRQoL of children surviving cancer and their parents

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**Keywords:** health related quality of life (HRQoL), survivorship, childhood cancer survivors, parents, psychological functioning, resiliency

**Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>HRQoL</td>
<td>Health related quality of life</td>
</tr>
<tr>
<td>CNS</td>
<td>Central nervous system</td>
</tr>
<tr>
<td>ICCC</td>
<td>International Classification of Childhood Cancer</td>
</tr>
<tr>
<td>ARIA</td>
<td>Accessibility Remoteness Index of Australia</td>
</tr>
<tr>
<td>CD-RISC2</td>
<td>2-item Connor-Davidson Resilience Scale</td>
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<td>MID</td>
<td>Minimally important difference</td>
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Abstract (250/250 words)

**Purpose:** Few studies have investigated the health-related quality of life (HRQoL) of young childhood cancer survivors and their parents. This study describes parent and child cancer survivor HRQoL compared to population norms and identifies factors influencing child and parent HRQoL.

**Methods:** We recruited parents of survivors who were currently <16 years, and >5 years post-diagnosis. Parents reported on their child’s HRQoL (Kidscreen-10), and their own HRQoL (EQ-5D-5L). Parents rated their resilience and fear of cancer recurrence and listed their child’s cancer-related late-effects.

**Results:** 182 parents of survivors (mean age=12.4 years old and 9.7 years post-diagnosis) participated. Parent-reported child HRQoL was significantly lower than population norms (48.4 v 50.7, p<.009). Parents most commonly reported that their child experienced sadness and loneliness (18.1%). Experiencing more late effects and receiving treatments other than surgery were associated with worse child HRQoL. Parents’ average HRQoL was high (0.90) and no different to population norms. However, 38.5% of parents reported HRQoL that was clinically meaningfully different from perfect health, and parents experienced more problems with anxiety/depression (43.4%) than population norms (24.7%, p<.0001). Worse child HRQoL, lower parent resilience, and higher fear of recurrence was associated with worse parent HRQoL.

**Conclusions:** Parents report that young survivors experience small but significant ongoing reductions in HRQoL. While overall mean levels of HRQoL were no different to population norms, a subset of parents reported HRQoL that was clinically meaningfully different from perfect health. Managing young survivors’ late effects and improving parents’ resilience through survivorship may improve HRQoL in long-term survivorship.
Introduction

Improvements in treatment protocols mean that more children are surviving cancer and living longer. However, life-saving cancer treatment results in heightened risks of mortality and morbidity during survivorship. Large cohort studies indicate that survivors of childhood cancer are at increased risk for second cancers, cardiovascular disease, pulmonary disease, and psychological morbidity. Studies of the prevalence of chronic health conditions indicate that between 75-98% of survivors will experience at least one late-effect of treatment as young adults, and that the risk of experiencing late-effects and second cancers increases as survivors’ age. Understanding the true burden of surviving childhood cancer is paramount to better tailoring health and psychological care throughout survivorship.

Quality of life is a subjective rating that an individual makes regarding their overall functioning. Quality of life encompasses the domains of physical, psychological, social and role functioning, and can also encompass functioning across other domains including spirituality and family functioning. Health-related quality of life (HRQoL) additionally considers functioning in the context of an individual’s health and illness symptoms. Assessment of HRQoL in cancer survivors allows the quantification of functioning during survivorship years. Identification of factors associated with worse HRQoL outcomes can inform practice and assist the development of services that are in line with survivors’ needs as they age.

Previous reviews suggest that while childhood cancer patients’ HRQoL is poor during treatment, survivors often report overall HRQoL on a par with their peers. However, a subset of survivors appear to be at risk of reduced HRQoL. Survivors who were diagnosed...
with central nervous system (CNS) tumours and treated with more intensive therapies (e.g. cranial radiation, transplant) report poor HRQoL, as do survivors from families with poor family functioning and low socio-economic backgrounds.\textsuperscript{9-12} Particular domains of functioning appear to be vulnerable in the years after treatment for paediatric cancer patients. Several studies have shown that psychological-emotional functioning and social functioning are two particular domains of life that continue to be impacted long after treatment completion.\textsuperscript{9-12,14}

Paediatric oncology has long recognised the interrelatedness of parent and child adjustment to cancer, and accordingly family-centred psychosocial care is considered fundamental.\textsuperscript{15} Parents’ wellbeing has the capacity to impact their child’s wellbeing and family functioning through cancer treatment and beyond.\textsuperscript{12,14,16} For example children of parents who experience more distress and react more to stress, self-report a significant impact on their own HRQoL.\textsuperscript{10,12} Conversely, a child’s wellbeing can impact parents’ wellbeing. For example when their child experiences more negative treatment side-effects, greater treatment intensity and disease severity, parents report worse reduced psychological wellbeing and functioning.\textsuperscript{15}

In the years after treatment completion, many families adjust to a “new normal”, however a subset continue to experience significant psychological distress which impacts their HRQoL.\textsuperscript{16,17} Mothers, parents with existing mental health concerns, and parents of children with difficulties adjusting to cancer diagnosis and treatment are at increased risk of poor HRQoL.\textsuperscript{15,16} Parent appraisals of their own social and emotional coping resources may be important determinants of HRQoL during survivorship. For example, parents of long-term survivors of brain tumours (10 years post-diagnosis), reported worse mental and physical HRQoL when they perceived themselves as having fewer emotional resources and their child
had poor peer relationships. The identification of risk factors is critical to preventing sustained poor HRQoL for both parents and young survivors.

Research has described the psychosocial outcomes of adult survivors of childhood cancer. Yet, few studies have specifically considered the HRQoL of young survivors who are still under the care of their parents. Given most childhood cancers are diagnosed in the first five years of life, the foundation for future wellbeing during survivorship is critically influenced by parents. Therefore, this study aimed to:

1. Describe the HRQoL of young survivors of childhood cancer and their parents, as compared to normative data, and
2. Identify factors associated with HRQoL among survivors of childhood cancer and their parents which may indicate who is at risk of reduced HRQoL.

Methods

Participants

Eligible participants were parents of children (aged <16 years) who were >5 years post any cancer diagnosis, had completed active treatment, and were alive and in remission. One parent per child was eligible to respond. We asked staff at the 11 pediatric hospitals in Australia and New Zealand to identify a random sample of around 200 potential participants who were <16 years of age when diagnosed, and were now >5 years post any cancer diagnosis and had completed active treatment through medical records. We then verified survivors’ vital status with the Births, Deaths and Marriages Registry in Australia and New Zealand (based on treating centre). After removing any deceased individuals, we checked contact details with Australian and New Zealand residential directories. We expected a high number to be uncontactable given that they were discharged from their hospital prior to the
study. We excluded parents with insufficient English to complete the questionnaire and those deemed inappropriate to contact by their oncologist (e.g. due to severe psychosocial challenges that would impair participation e.g. psychosis).

**Procedure**

We mailed potential participants a study pack that included an invitation letter from the lead clinician at the hospital at which they were treated, consent form, questionnaire (and link to online version of the questionnaire), and postage-paid envelope. We followed-up non-respondents via telephone after four weeks, up to four times and resent the questionnaire up to two times. We prevented responses from duplicate IP addresses, and all responses to the questionnaire were anonymous. The study was approved by the relevant ethics authority for each hospital (Lead site reference 12/173 12/POWH/345) and was endorsed by the Australian and New Zealand Children’s Haematology Oncology Group. Data available on request due to privacy/ethical restrictions.

**Measures**

*Clinical and demographic factors* were reported by parents and included their child’s diagnosis, treatment type received, child’s current age, year of diagnosis, sex, whether they were attending a long-term follow-up clinic for survivorship care, and how satisfied they were with this care (5 response options ranging from “very unsatisfied” to “very satisfied”). Parents self-reported their current place of residence, level of education and relationship to the child (e.g. mother, father). We coded place of residence into major city (metropolitan) or rural and regional using the Accessibility Remoteness Index of Australia (ARIA) classification for Australian participants and the New Zealand Area Codebook for New Zealand participants.
Parent quality of life was assessed using the EQ-5D-5L, a validated quality of life measure with five items assessing mobility, self-care, ability to participate in usual activities, pain/discomfort, and anxiety/depression; answered on a Likert scale with response options ranging from “no problems” to “I am unable to”. A visual analogue scale regarding their overall health was also included asking participants to rate their health today on a scale of 0-100, where 0 is the worst possible health they can imagine and 100 is the best possible health they can imagine. The first five items are analysed together to determine a quality of life index value, while the last indicates current health perceptions. Index values range from 0 to 1 (0=death, 1=perfect health). We calculated the EQ-5D-5L index using the UK population value set to enable comparison to an Australian normative population which also employed the UK value set in calculating HRQoL index scores. The Australian normative data are derived from 2,908 adults aged over 15 years of age. We also calculated the proportion of parents reporting any domain-specific difficulties according to developer instructions.

Parent-reported child quality of life was assessed using the Kidscreen-10, a validated parent proxy measure of their child’s global HRQoL. This 10-item scale addresses functioning in emotional wellbeing, social functioning, activity levels, school performance, and quality of relationships with parents/caregivers and friends. Responses are a Likert scale and range from “not at all/never” to “extremely/always”. We summed scores across items, assigned Rasch person parameters and then transformed these values into a T score with a mean of 50 and a standard deviation of 10 according to the Kidscreen Manual. Higher scores indicate better HRQoL. We also calculated the proportion of parents reporting item specific problems for their child (0=not at all/never a problem, 1=any frequency level of problem). We used published norms derived from 16,237 parents who provided Kidscreen-10 proxy responses.
Late-effects were measured using a purpose designed question. We asked parents to indicate (yes/no) on a list of late-effects all the health issues that they believed their child had experienced associated with their child’s cancer or treatment that had occurred since finishing treatment (see Supplementary material). We summed the number of late effects to get the total number survivors were currently experiencing.

Fear of cancer recurrence and fear of late effects were assessed using two purpose designed questions. We asked parents to indicate how worried or anxious about their child experiencing a cancer recurrence or late-effects on a scale with five response options ranging from “not at all” to “a great deal”.

Parent resilience was measured using the 2-item Connor-Davidson Resilience Scale (CD-RISC2). The two items assess whether the participant is “Able to adapt to change,” and “Tends to bounce back after hardship or illness”. Responses range from “not at all” to “nearly all of the time”.

Data Analysis

We used IBM SPSS (IBM Corp, Version 22.0, Armonk, NY) for statistical analyses. We used means, standard deviations and proportions where appropriate to describe our sample. For Aim 1, we used two-tailed Student’s t-tests to compare the HRQoL index and VAS on the EQ-5D-5L to Australian normative data. We were unable to do age-wise comparisons as we did not collect parent age, so we used the overall mean Index score. We used Chi-square goodness of fit tests to compare the proportion of participating parents endorsing problems or not across the five domains of HRQoL as measured by the EQ-5D-5L. We considered a reduction of 0.08 on the HRQoL and 7 on the VAS to be indicative of minimally important difference (MID) in HRQoL. For parent-reported child HRQoL, we compared the
Kidscreen-10 T-score to published norms,\textsuperscript{23} using two-tailed Student t-test. We also considered the rate at which parents reported problems for their child across the different items of the Kidscreen-10 using Cochrane’s Q test, with a Bonferroni correction for pairwise comparisons.

For Aim 2, to identify factors associated with HRQoL for parents of childhood cancer survivors (as measured by the EQ-5D-5L index score), and parent-reported child HRQoL (as measured by the Kidscreen-10 total score), we conducted a series of simple linear regressions for continuous and dichotomous variables, and one-way ANOVA for categorical variables with more than two categories. We considered child clinical variables, total number of late-effects reported, parent socio-demographic variables, parent fear of cancer recurrence and late effects, and parent resilience. We coded child diagnosis according to International Classification of Childhood Cancer (ICCC) into leukaemia, lymphoma, brain cancer and other. We also included child HRQoL when considering parent HRQoL and vice versa. We included variables from the univariate analyses of parent and child HRQoL with \(p<0.2\) in the subsequent multivariable analyses. Results were considered significant if \(p<0.05\).

**Results**

We approached 308 parents of childhood cancer survivors and recruited 182 parents (59.1% response rate). Parent participants were mostly mothers (80%) of childhood cancer survivors who were on average 12.4 years old (range= 7-15 years) and 9.7 years since diagnosis (range= 5-15 years, Table 1). Just over a half of survivors were male (54.2%), many had survived leukaemia (46.4%) and the majority were treated with chemotherapy (94.9%). There was no difference between participating and non-participating parents’ residential location or child characteristics of age and sex (\(p>.05\)).
On average, parents reported that survivors had experienced 3.2 late effects relating to their cancer and/or treatment (SD=3.1, range=0–15). The five most commonly reported late-effects were dental problems (43.4%), fatigue (38.3%), problems relating to immunity (37.7%), memory and learning problems (33.7%) and emotional difficulties (30.3%). Parents commonly reported that they were “a little worried” or “somewhat worried” about their child having a cancer recurrence (63.2%) or late-effects (64.9%), and 23.6% and 25.3% reported they were worried “a lot” or “a great deal” about cancer recurrence or late-effects, respectively. Parents had a mean resilience score of 8.56 (Range: 2–10, SD:1.5). The majority of parents reported that their child currently attended a long-term follow-up clinic (78.5%) for survivorship care. Parents reported that they were “satisfied” (42.9%) or “very satisfied” (37.3%) with the long-term follow-up care they received.

**Parent-reported child HRQoL**

On average, parents reported their child’s global HRQoL was 48.4 (SD=10.8, range= 27.3-87.9). Parents indicated that their child ‘always’ or ‘very often’ had high HRQoL in most domains, providing the highest rating for ‘felt fit and well’ (78.6%, Figure 1) followed by ‘had fun with their friends’ (74.6%). When compared to normative data from children without special health care needs, childhood cancer survivors had significantly lower parent-reported overall HRQoL (48.4 versus 50.6, p<0.009). Comparison across items in the Kidscreen-10 within our sample using the Cochran’s Q test indicated that parents were significantly more likely to report that their child had problems with feeling lonely and feeling sad compared to other items (Figure 1).

**Parent HRQoL**
Survivors’ parents’ average HRQoL was 0.90 (SD=0.12, range= 0.14–1.00) and 38.5% of parents reported a difference from perfect health.\textsuperscript{25} Parents commonly indicated problems relating to anxiety/depression (43.3%), followed by pain (42.3%, Figure 2). On average, parents reported their overall health today as 80.1 out of 100 (SD=15.0, range= 30–100). Parents’ overall HRQoL was no different to Australian normative data on both the index score (population mean=0.91, \textit{p}=0.475) and overall health rating (population mean=78.6, \textit{p}=0.163). When considering each domain of HRQoL, the proportion of survivors’ parents experiencing problems did not differ from Australian norms on pain/discomfort (\textit{p}=0.570).

Significantly more survivors’ parents reported experiencing problems with anxiety/depression (43.4%) compared to Australian norms (24.7%, \textit{p}<0.0001). Survivors’ parents were less likely to report problems with mobility (\textit{p}<0.0001), self-care (\textit{p}=0.024), and usual activities (\textit{p}=0.005) when compared to the general population.

\textit{Determinants of child HRQoL}

We examined the impact that parent and child factors had on overall child HRQoL. In multiple linear regression (Table 2), receiving treatments other than surgery (i.e. chemotherapy, radiotherapy, transplant, \textit{p}=0.015) and experiencing more late-effects \textit{(p}=0.003) were significantly associated with worse parent-reported child HRQoL. No other factors were significantly associated with parent-reported child HRQoL.

In post-hoc analyses we sought to determine factors associated with parents rating their child as feeling sad and feeling lonely on the Kidscreen-10. In the multivariable analysis only lower parent resilience was associated with a greater likelihood of their child experiencing sadness (\textit{p}=0.039, OR=0.757, 95\%CI: 0.581-0.986). Parents were more likely to report their child experienced loneliness if they had a parent income >$60,000AUD p.a. (\textit{p}=0.024, OR:
1.001, 95%CI: 1.000-1.003) or lower parent resilience (p=0.036, OR:0.759, 95%CI: 0.587-0.982).

**Determinants of parent HRQoL**

Lower parent HRQoL was significantly associated with lower child HRQoL (p=0.015), greater fear that cancer would recur in their child (p=0.001), and lower levels of parent resilience (p=0.015; Table 2). No other factors were significant, including age, sex, diagnosis, treatment(s), number of late effects experienced, or time since diagnosis.

Given psychological functioning was a particularly vulnerable area of HRQoL for parents of survivors, in post-hoc analyses we sought to determine factors associated with ratings of problems with anxiety and depression. The following factors were significantly associated with more anxiety and depression problems in the final logistic multivariable model: child’s diagnosis of brain cancer (p=0.014, OR=22.101, 95%CI: 1.861-262.514), and lower parent resilience (p<0.0001, OR 0.542 95%CI: 0.391-0.750). Overall, lower child HRQoL as measured by parent report on the Kidscreen-10 was marginally associated with increased likelihood of parents reporting problems with anxiety and depression (p=0.053, OR 0.960 95%CI 0.921-1.000). No other factors were associated with likelihood of parents reporting problems with anxiety and depression.

**Discussion**

In our study, parents reported that their child’s overall HRQoL was worse than normative data. When individual domains of child HRQoL were considered, parents reported that their child survivor was more likely to experience sadness and loneliness compared to all other areas of functioning except feeling full of energy. Parents were more likely to report that their
child had poor HRQoL if they had received treatments other than surgery and had more health issues (late-effects) after treatment. Lower parent resilience was related to likelihood of parent-reported child sadness and loneliness. Parents of childhood cancer survivors reported that their own overall HRQoL in survivorship years was no different to normative data. However, 43.5% parents reported problems with anxiety and/or depression on the EQ-5D-5L. Parents at risk of poor HRQoL were those reporting lower child HRQoL, lower levels of resilience and greater worry about the risk of cancer recurrence in their child. No treatment or diagnostic factors were consistently associated with parent HRQoL.

Similar to existing literature,9 our results show psychosocial functioning as reported by parents of young survivors may be an area of ongoing vulnerability years after treatment completion. Approximately 18% of parents reported that their child experienced problems with feeling sad and feeling lonely. Consistent with others,15,17 our results indicate that parents of survivors adapt relatively well to their child’s cancer when considering overall HRQoL or overall functioning in survivorship. Yet similarly parents may also remain psychologically vulnerable long after treatment completion. Qualitative parent interviews in other studies complement our results and suggest parents and young survivors continue to grapple with the emotional upheaval and disruption that occurs during diagnosis and treatment in survivorship.26

We found physical symptoms, as measured by more late-effects experienced in survivorship, and having received treatments other than surgery (i.e. chemotherapy, radiotherapy and transplant) were significantly associated with worse parent-reported overall child HRQoL.12 These results may be related to the symptom burden and concomitant medical treatment needs experienced by patients and the associated caregiving burden experienced by parents during survivorship. For example, parent’s perceptions of their child’s cancer severity and
interference with life have been found to be significantly associated with ratings of HRQoL.\textsuperscript{27} However, caregiving burden mediated this relationship, with high caregiving burden associated with reduced HRQoL.\textsuperscript{27} Previous research has found that some diagnoses (i.e. brain cancer) and more intense treatment (severity and frequency of hospitalizations) are associated with worse parent psychological functioning.\textsuperscript{28,29} Whilst we found no association between parent HRQoL and treatment and diagnostic factors in our study, we did find that having a child diagnosed with brain cancer was significantly associated with worse psychological functioning in post-hoc analyses.

Our results reinforce the interrelatedness of child and parent HRQoL. Parents who reported they were generally psychological resilient also reported better HRQoL for their child and themselves. Similarly, parents who perceive their child’s cancer as more uncertain, and have negative attitudes towards illness, are more likely to report worse adjustment and HRQoL for themselves and their child.\textsuperscript{30} Therefore, parent adjustment and coping with their child’s diagnosis may be critical for determining later psychological functioning for the whole family,\textsuperscript{12,16,26,29} potentially more so than diagnosis, treatment, subsequent late-effects. Further comprehensive research on parental psychological functioning and its influence on their child’s health care engagement and survivorship care is therefore warranted.

\textit{Clinical implications}

Our results indicate that young survivors experience reduced HRQoL compared to norms and a subset of parents experience HRQoL that was clinically meaningfully different from perfect health. Accordingly, improving patient and parent HRQoL should be a goal of survivorship care. Our data indicating potential for ongoing psychological impact, and no consistent relationship with clinical/demographic factors, support arguments for implementing universal psychosocial screening and access to appropriate psychological support for children and
parents where needed as part of routine long-term follow-up.\textsuperscript{14,15} Paediatric oncology survivorship programs may benefit from embedded psychosocial care, yet many clinics lack dedicated psychological support and screening.\textsuperscript{31} Focusing on parent resilience, together with addressing unmet psychological and information needs,\textsuperscript{32} may support parent and child HRQoL during survivorship.

\textit{Limitations}

Our sample consisted of mostly well-educated mothers and our results therefore may not accurately reflect the HRQoL of fathers of childhood cancer survivors. While fathers may initially adapt faster to their child’s life threatening illness/injury, they may experience worse mental health in the long-term when compared to mothers.\textsuperscript{33} Future research recruiting both parents would allow better understanding of the impact of childhood cancer on the family and parent’s long-term HRQoL. Furthermore, lower educational attainment is a risk factor for poorer HRQoL,\textsuperscript{34} and the results obtained here may not reflect the experiences of parents with lower educational attainment during their child’s survivorship years.

Our response rate was moderate, and lower than published psycho-oncology study participation rates.\textsuperscript{35} Although there were no differences between participating and non-participating parents on available demographic characteristics, non-participating parents may have been those experiencing greater psychological concerns. We were also unable to undertake age-stratified comparisons on parent HRQoL. Combined with our sample size, the generalizability of our results may be compromised. We relied on parent proxy ratings for child HRQoL, which may be discrepant with child self-ratings. Namely, children tend to rate themselves as having better HRQoL than their parents.\textsuperscript{36} However parent perceptions of their child’s HRQoL may influence healthcare engagement, and transition to self-management of medical follow-up as young survivors become adults.\textsuperscript{15,37} Research suggests parent proxy
ratings and child ratings of HRQoL are similar, especially when the child is younger (as in our sample), and when considering domains of HRQoL that are readily observable.\textsuperscript{36,38,39} However, future research would benefit from including child-reported HRQoL. A further limitation is our reliance on a sole informant (i.e. parent) which may influence the observed relationship between parent and child HRQoL and the predictors due to common method variance.

\textit{Conclusions}

In our study, parents reported that their child experienced reduced overall HRQoL, while overall parent HRQoL was no different to norms. There was some evidence for poor psychosocial functioning among both survivors and parents warranting further investigation. Our study indicates modifiable factors, such as fear of cancer recurrence and fear of late-effects, and parent resilience may play a role in determining child and parent HRQoL during survivorship. Models of long-term follow-up care emphasise managing late effects and possible second cancers through identifying patients at high risk due to the treatments received.\textsuperscript{40,41} Such risk-based approaches may benefit from taking into account the potential for poor HRQoL, however future research is needed on the best ways to identify young survivors, and their parents, at risk of poor HRQoL. Development and evaluation of family-centred and resiliency programs could ultimately support not just childhood cancer survivors’ but also parents’ adjustment during survivorship.

\textbf{References}


Figure Legends

Figure 1. Childhood cancer survivor HRQoL.

Notes. In post-hoc Bonferroni corrected pairwise comparisons, *Parents were more likely to report their child felt sad (18.1%) than having problems with having fun with friends (8.3%, p=0.016), paying attention (7.7%, p=0.007), parents treated them fairly (6.6%, p=0.003), got on well at school (6.6%, p=0.003), was fit and well (6.6%, p=0.001), being able to do the things they want (2.2%, p<0.001), had enough time for themselves (2.2%, p<0.001). #Parents were more likely to report their child felt lonely (18.1%) than having problems with having fun with friends (8.3%, p=0.007), paying attention (7.7%, p=0.003), parents treated them fairly (6.6%, p=0.001), got on well at school (6.6%, p=0.001), was fit and well (6.6%, p=0.001), being able to do the things they want (2.2%, p<0.001), had enough time for themselves (2.2%, p<0.001).
Figure 2. Parents of childhood cancer HRQoL domains compared to population norms

Note. *Significantly different at p<.05

TABLE 1 Parent and child demographics.

<table>
<thead>
<tr>
<th>Parent demographics (n=182)</th>
<th>N (%)</th>
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<td>Education level&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>Employment&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Not currently employed</td>
<td>35 (19.2)</td>
</tr>
<tr>
<td>Currently employed (including full and part-time work)</td>
<td>144 (79.1)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Not currently married/defacto</td>
<td>25 (13.7)</td>
</tr>
<tr>
<td>Currently married/defacto</td>
<td>157 (86.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child demographics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>99 (54.4)</td>
</tr>
<tr>
<td>Age (current years, Mean:SD)</td>
<td>12.4 (2.2)</td>
</tr>
<tr>
<td>Range</td>
<td>7-15 years</td>
</tr>
<tr>
<td>Time since diagnosis (Mean:SD)</td>
<td>9.7 (2.1)</td>
</tr>
<tr>
<td>Range</td>
<td>5-15 years</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>ALL &amp; AML</td>
<td>82 (45.1)</td>
</tr>
<tr>
<td>Factor</td>
<td>Child HRQoL (Kidscreen-10 T score)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td></td>
<td>Univariate p</td>
</tr>
<tr>
<td><strong>Child factors</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>0.481</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td>0.186*</td>
</tr>
<tr>
<td><strong>Diagnosis (overall)</strong></td>
<td>0.485</td>
</tr>
<tr>
<td><strong>Surgery</strong></td>
<td>0.004*</td>
</tr>
</tbody>
</table>

**Notes.** *missing 11, **missing 2; /*missing 19; */missing 19; /*missing 3; ALL Acute Lymphoblastic Leukaemia; AML Acute Myeloid Leukaemia

**TABLE 2** Associations with child and parent HRQoL.
<table>
<thead>
<tr>
<th>diagnosis</th>
<th>&lt;.0001*</th>
<th>0.003</th>
<th>0.99</th>
<th>-1.647</th>
<th>-0.351</th>
<th>0.241</th>
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</thead>
<tbody>
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<td>Number of health issues</td>
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<tr>
<td>LTFU attendance</td>
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<td>LTFU satisfaction</td>
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<tr>
<td>Child HRQoL (Kidscreen-10 T)</td>
<td>n/a</td>
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<tr>
<td>Parent factors</td>
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<tr>
<td>Parent sex</td>
<td>0.356</td>
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<tr>
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<td>0.551</td>
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<td>Marital status</td>
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<tr>
<td>Place of residence</td>
<td>0.889</td>
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<tr>
<td>Employment</td>
<td>0.43</td>
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<tr>
<td>Income</td>
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<tr>
<td>Resilience</td>
<td>0.002*</td>
<td>0.073</td>
<td>1.06</td>
<td>-0.102</td>
<td>2.223</td>
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<tr>
<td>Worried about cancer recurrence</td>
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<td></td>
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<tr>
<td>Worried about late effects</td>
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<td></td>
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<tr>
<td>Parent HRQoL (EQ-5D-5L index)</td>
<td>0.009*</td>
<td>0.103</td>
<td>10.9</td>
<td>-2.246</td>
<td>24.063</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Notes. *entered into multiple linear regression. #excluded due to high correlation with worries about cancer. n/a not applicable.
Author/s:
Fardell, JE; Wakefield, CE; De Abreu Lourenco, R; Signorelli, C; McCarthy, M; McLoone, J; Osborn, M; Gabriel, M; Anazodo, A; Alvaro, F; Lockwood, L; Walwyn, T; Skeen, J; Tillemans, R; Cohn, RJ; ANZCHOG Survivorship Group,

Title:
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Date:
2021-12

Citation:

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http://hdl.handle.net/11343/299064