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Could we use parent report as a valid proxy of child report on anxiety, depression, and distress? A systematic investigation of father-mother-child triads in children successfully treated for leukemia.

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Short running title: Parent-child ratings of distress in young survivors

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Abbreviation table:

Abbreviation	Full term
ICC	Intraclass correlation coefficients
ALL	Acute lymphoblastic leukemia
DFCI	Dana Farber Cancer Institute
SJUHC	Sainte-Justine University Health Center
BYI	Beck Youth Inventories
DRS	Distress Rating Scale
DT	Distress Thermometer
BSI-18	Brief Symptom Inventory-18

Abstract

Background: Systematic assessment of emotional distress is recommended in after care. Yet, it is unclear if parent report may be used as a proxy of child report. The aim of this study was to assess agreements and differences and explore possible moderators of disagreement between child and parent ratings. **Methods:** Sixty-two young survivors treated for Acute Lymphoblastic Leukemia (9-18 years) and both parents responded to the Beck Youth Inventory (anxiety and depression) and the Distress Rating Scale on the child's status. Parents completed the Brief Symptom Inventory-18 on their own psychological status. Systematic analyses of agreement and differences were performed. **Results:** Mother-child and father-child agreements were fair on anxiety, depression, and distress (median ICC=0.37). Differences between parents and children were medium sized (median $d=0.55$) with parents giving higher scores than their children on anxiety, depression and distress. Mothers reported distress more frequently than fathers (39 vs 17%) when children reported none. The child being a girl and lower parental income were associated with lower agreement in fathers when rating child distress. Higher levels of parental psychological symptoms were consistently associated with lower agreement. **Conclusions:** Parent-child differences when rating adolescent survivors' difficulties may be more important than previously thought. Parent report probably cannot be considered as a valid proxy of older child report on such internalized domains as anxiety, depression, or distress in the after-care clinic. Parents' report is also likely to be influenced by their own mood, a factor that should be corrected for when using their report.

1 **Background**

2 Recent standardized guidelines of care for pediatric cancer survivors have highlighted a
3 high quality of evidence on heightened distress, anxiety and depression in this population and
4 formulated strong-level recommendations for systematic psychosocial screening¹. Thorough
5 follow-ups and yearly psychosocial screening are recommended¹⁻⁴. Psychosocial assessment is
6 essential as it allows for accurate detection of mental health concerns and very probably favors
7 the delivery of targeted care¹⁻⁴. Survivors themselves have considered the evaluation of their
8 psychological well-being as very important⁵.

9 This vulnerable population is characterized by higher levels of internalizing symptoms
10 and lower levels of externalizing symptoms⁶. Research estimated that 13-22% of teenagers who
11 survived childhood cancer self-reported psychological difficulties and that their clinical risk for
12 anxiety and depression was also greater than in the normative population⁷⁻⁹. Importantly, cancer
13 related distress is more prevalent in at risk groups such as survivors who are older children or
14 adolescents^{10,11}. Regular systematic evaluations may help combat unrecognized and
15 undertreatment of psychological problems in this population^{12,13}.

16 Systematic evaluation can be conducted by using both child and parent reports. When the
17 self-report of a young patient is difficult to get or believed to be unreliable, common practice is
18 to rely on other informants' ratings like that of a parent or teacher. Parents, as main caregivers,
19 are in a prime position to observe their children and are likely to be knowledgeable about their
20 experience^{14,15}. As a proportion of young survivors may develop neurocognitive difficulties
21 which could imperil the accuracy of self-report, parents' reports may be an essential source of
22 information. In fact, survivors often experience adverse effects resulting in symptoms like
23 fatigue, executive function deficits and concentration difficulties^{7,16-18} that can be detrimental for

24 skills necessary to form an accurate self-judgment or a realistic appraisal of the disease's
25 implications^{19,20}.

26 Studies in healthy and clinical populations have found that parents' ratings of children's
27 symptoms and children's self-reported experiences may be discrepant, with greater disagreement
28 being observed for internalizing symptoms²¹⁻²⁵. Recent studies at various stages of cancer have
29 found low to moderate parent-child agreement on aspects such as self-reported adverse events or
30 health-related quality of life²⁶⁻³³. To our knowledge, only three studies have compared parent and
31 child ratings of child distress in the context of pediatric oncology. Two of these examined
32 parents' and children's ratings of child distress on versions of the Distress Thermometer (DT).
33 They both found moderate parent-child agreement at various stages of cancer³⁴ and in a mixed
34 chronic disease sample (including cancer)³⁵. The other compared parents' and children's ratings
35 of child anxiety during cancer treatment on the Pediatric Quality of Life Inventory and reported
36 higher parental ratings³⁶. The results of these studies are difficult to interpret as these studies did
37 not provide detailed demographic information on the informants nor the instructions given to
38 parents. They also had somewhat heterogeneous samples.

39 Previous research suggested that higher agreement levels between parents and children
40 ratings could be associated with a number of factors: a younger child¹⁵, higher parental income,
41 lower maternal anxiety or depression¹⁶⁻²², or lower repression in children³³. This is consistent
42 with a meta-analysis which found higher levels of agreement between parents and school-age
43 children in comparison to parents and teenagers on psychological symptoms in a non-clinical
44 sample²¹. Yet, most studies investigating these associations did not partial out the effect of child
45 ratings from the parent ratings to study further moderators. Rare studies had samples of parental
46 raters that include both mothers and fathers³⁷. They were also limited as they did not distinguish

47 between mothers' and fathers' ratings nor did they separately investigate the role of father's and
48 mother's psychological symptoms. No studies have yet examined parents' and children's ratings
49 of child anxiety, depression and distress in young survivors of childhood cancer (<18 years of
50 age). Given that parents differ in their intimacy to children and that those with a child who
51 survived cancer experience significant long-term distress, it is necessary to separately examine
52 parental characteristics that may influence levels of agreement³⁸⁻⁴⁰.

53 The first objective of the present study was to assess levels of agreement in mother-child
54 and father-child dyads on ratings of child anxiety, depression and distress. Following previous
55 evidence, we expected small to moderate levels of agreement, with Intraclass Correlation
56 Coefficients (ICCs) of 0.30-0.50. The second objective was to evaluate the size of differences in
57 ratings of anxiety, depression and distress between children, mothers and fathers. We expected
58 no more than moderate differences between parents and children ($d < 0.50$) and a tendency for
59 parents to report higher ratings than children. The third objective was to explore associations
60 with disagreements to identify potential moderators. We expected higher child age, lower
61 parental income and elevated levels of parental psychological symptoms to be related with larger
62 disagreements.

63 **Methods**

64 **Study participants**

65 Participants were successfully treated for acute lymphoblastic leukemia (ALL) with Dana
66 Farber Cancer Institute (DFCI) protocols at Sainte-Justine University Health Center (SJUHC),
67 PETALE Cohort⁴¹. They were at least five years post diagnosis, without relapse and no second
68 cancer or stem cell transplant at recall. Two-hundred and fifty-one survivors and their families
69 were contacted, 225 agreed to participate and we obtained full data from 222 survivors (response

70 rate 88%), 209 mothers (83%), and 174 fathers (69%). To be eligible for the present study,
71 survivors had to be less than 18 years old and still live with their parents. Following those
72 criteria, 88 survivors were eligible for the present study. Only complete mother, father and child
73 triads were retained to enable accurate comparison between dyads. One triad was excluded due
74 to missing data. Our final sample comprised 62 triads and mostly consisted of Caucasians (Table
75 1). Children's median age was 16 years, mothers' ages ranged from 35-55 years and fathers' age
76 from 38-63 years. Median time since diagnosis was 12 years. All mothers and fathers were
77 biological parents who took care of their child at the time of diagnosis. Differences between
78 participants and non-responders are unknown.

79 **Procedure and data collection**

80 Approval for the protocol was received from the SJUHC Ethics Committee. Participants
81 were contacted by telephone and consent forms were sent to those interested. All parents signed
82 the consent forms for themselves and for their child aged less than 18. Children provided their
83 informed assent. Recruitment was organized at the long-term follow up clinic of SJUHC. During
84 the child's research visit at the clinic, children and parents responded to self-reported
85 questionnaires. If only one parent was present during the visit, he/she would bring the
86 questionnaire in a sealed envelope to be filled by his/her partner at home and send them back to
87 our centre within one week. If a survivor asked for help to complete the questionnaires, a
88 research assistant was available to provide assistance by reading sentences or explaining the
89 meaning of a word. Complete biological measures and a physical health examination were also
90 taken during the child's research visit to the clinic⁴¹. Participants were compensated to cover
91 expenses for meals and parking. Upon receipt, children's and parents' responses were

92 screened to identify clinical levels of distress. Positive cases were referred to the psychosocial
93 services of the clinic.

94 **Measures**

95 *Child anxiety and depression*

96 Child anxiety and depression were assessed with the Beck Youth Inventories (BYI
97 modules Anxiety and Depression). This self-reported instrument documents psychological status
98 of children and adolescents from 7 to 18 years⁴². In our sample, internal consistency coefficients
99 were .90 for the anxiety module and .89 for the depression module. Raw scores from the 20
100 likert-type items (0= never, 3=always) were transformed into T-scores for analyses and
101 interpretation. T-scores identify anxiety and depression severity levels: <55 = mild, 55–59 =
102 moderate, 60–69 = severe and >70 = extreme⁴².

103 *Child distress*

104 The distress rating scale (DRS) is a single brief visual numeric scale (0= no distress, 10=
105 high distress) measuring distress experienced over the last week³⁴. For children at different
106 stages of the cancer continuum, the instrument has shown reasonable convergent validity³⁴.
107 Although no cut points have been validated with children yet, a score of 4 may be indicative of
108 significant distress in cancer survivors⁴³.

109 *Parent report of child anxiety, depression and distress*

110 Independently from their children, parents were asked to provide a proxy assessment of
111 their child's anxiety, depression and distress. In the conceptual literature, two methods have been
112 available to obtain a proxy assessment¹⁵. Respondents can either be asked to assess a patient by
113 answering based on their own opinion or can be asked to infer the experience of the patient¹⁵. In
114 the present study, parents were instructed to infer the experience of their child, i.e. to take their
115 perspective while completing analogous versions of the BYI and DRS. Additional instructions

116 stated: “Answer each question the way you think your child has answered by taking the
117 perspective of your child”. Previous research in oncology and other conditions has shown that
118 such instructions prompted perspective-taking responses on internalized symptoms⁴⁴⁻⁴⁷. This was
119 done in order to elicit a substitute judgment from the parent that mirrors the child’s personal
120 impression about their anxiety, depression, and distress. This was preferred here since anxiety,
121 depression, and distress are internalized symptoms, the best source of information lying with the
122 survivor’s experience himself.

123 *Parental psychological symptoms*

124 The Brief Symptom Inventory-18 (BSI-18) evaluated psychological symptoms in parents.
125 The instrument is comprised of three subscales (somatization, depression and anxiety) and a
126 global distress score⁴⁸. It assesses distress experienced in the last week on 18 items scored on 5
127 points each (0=not at all, 4=extremely)³¹. The BSI-18 is commonly used to indicate distress
128 levels in parents of sick children³⁹. The scales showed good internal consistency in our sample
129 ($\alpha=0.89-0.93$). Raw scores are converted into T-scores for further analyses. A cut-off of 63 on
130 scales is interpreted as a risk to have poor mental health or experience significant distress⁴⁸.

131 *Sociodemographic variables*

132 A demographic questionnaire assessed parents’ demographic information to obtain data
133 on sex, age, income, education, marital status, and ethnicity. Clinical history, ALL risk status and
134 treatment information were obtained from the child medical records.

135 **Statistical analyses**

136 All study variables respected criteria for normal distributions⁴⁹. A series of ICCs were
137 computed to evaluate agreement between child and parent report on anxiety, depression and
138 distress. Coefficients <0.40 indicate poor agreement, 0.40-0.59 fair agreement, 0.60-0.74 good

139 agreement, and ≥ 0.75 excellent agreement⁵⁰. ICCs could also be compared based on their
140 confidence intervals. We also computed percentage of agreement in parent-child dyads when
141 measures were treated according to cut-points.

142 Paired t-tests and Cohen's d were computed to assess differences between children's and
143 parents' ratings of child anxiety, depression and distress. Bland-Altman plots evaluated the
144 magnitude of the differences in dyads as a function of the means to explore for systematic
145 patterns. For informative purposes, additional results comparing mothers' and fathers' ratings of
146 child anxiety, depression and distress were also performed (supplementary material online).

147 We used stepwise multiple regressions to explain disagreements between parents' and
148 children's ratings. Analyses were performed separately for both parents. Using parents' ratings
149 as the dependent variable, children's ratings were entered into the first block so that the second
150 block addressed the residual variance of parental ratings controlling for children's ratings. This
151 residual variance was a measure of disagreement between parents' and children's ratings. The
152 second block included alternatively: 1) child and parent characteristics (child age, child sex,
153 parental income) 2) parental psychological symptoms. We used the SPSS statistics 22 software
154 to conduct all analyses. A value of $p < 0.05$ was set for statistical significance.

155 **Results**

156 **Parent-child agreement**

157 On average, children reported normative anxiety levels ($T=46.87 \pm 8.67$), with 18%
158 reporting mild to severe levels of anxiety, depression levels ($T=45.24 \pm 7.03$), with 12% reporting
159 mild to severe levels of depression, and distress levels ($M=2.40 \pm 2.37$), with 26% of the children
160 showing 'elevated' levels (Table 2). Parents also reported low global distress on their own status,
161 with only 6% of fathers and 8% of mothers showing significant distress on the BSI-18.

162 Table 2 presents agreement levels between children and each of their parents. Mother-
163 child agreement ranged from poor to fair (ICC=0.23-0.47) and was lowest on ratings of anxiety.
164 Father-child agreement also ranged from poor to fair (ICC=0.17-0.43). Notably, father-child
165 agreement was not significantly different from zero on distress (ICC=0.17, $p<0.10$). Overall,
166 limited agreement was found between parents' and children's ratings of anxiety, depression and
167 distress. These observations were confirmed when examining parent-child agreement on
168 measures treated with pre-validated cut-points (supplementary Tables S1-2). Interestingly, we
169 found that mothers reported more frequently distress on the DRS than fathers when the child
170 reported none (39 vs 17%) but this was not the case on the more 'objective' measures from the
171 BYI. On all measures, the reports of anxiety, depression and distress by both parents when the
172 child reported these as present were not different than chance (median agreement 52.5%) (Tables
173 S1 and S2).

174 **Parent-child differences**

175 We found medium differences on anxiety ($d=0.50$) and depression ($d=0.66$), and small
176 differences on distress ($d=0.35$) between mothers and children. Similarly, ratings indicated
177 medium differences between fathers and children on anxiety ($d=0.60$) and depression ($d=0.59$).
178 Both parents had higher ratings than children on anxiety and depression but only mothers had
179 higher ratings than children on distress (Table 2, Table S2).

180 Figure 1 illustrates the magnitude of the parent-child differences. No systematic
181 relationships were found between raw differences and levels of anxiety, depression and distress,
182 suggesting that the differences on ratings of anxiety, depression and distress were not influenced
183 by severity. However, when exploring relationships with absolute differences, significant
184 associations revealed that severity on distress was associated with higher differences both in

185 fathers and mothers (Kendall $\tau_s = 0.38$ $ps < .001$), suggesting that differences occur more
186 frequently when distress is higher and in both directions parent>child rating and child>parent
187 rating. Limits of agreement and measurement errors were large which indicated high variability
188 of differences in ratings (supplementary Table S5).

189 **Predictors of parental ratings**

190 When exploring predictors with hierarchical regressions, we found that parental ratings
191 were associated with child sex, parental income and parental psychological status once children's
192 ratings were controlled for (Table 3). A larger residual variance from Block 1, or larger
193 disagreement, was thus associated with the child being a girl and with lower parental income for
194 fathers' ratings of child distress. No effect was associated with child age.

195 When exploring the role of parents' psychological status, we found that larger
196 disagreements on ratings of child depression were associated with higher levels of maternal
197 anxiety and paternal distress. A larger disagreement on ratings of child anxiety was associated
198 with higher paternal distress. Also, a larger disagreement on ratings of child distress was
199 associated with higher maternal distress (Table 3). Thus, elevated parental psychological
200 symptoms were consistently associated with larger parent-child disagreement. Yet, these
201 predictors only explained a small percentage of the residual variance ($\Delta R^2 = 0.10$) which suggest
202 that other non-measured factors were involved in disagreement.

203 **Discussion**

204 The current study examined mother, father and self-reports of psychological status in
205 adolescents who have lived most of their lives as childhood cancer survivors. In 62 triads, we
206 found limited mother-child and father-child agreement on anxiety, depression and distress.
207 Medium differences indicated that parental mean ratings were higher on all measures of child

208 psychological status. An important result was that elevated parental anxiety and distress were
209 associated with larger disagreements for ratings of child anxiety, depression and distress.

210 The finding that parent-child agreement was low on anxiety, depression and distress is in
211 line with a non-cancer body of literature in the domain of quality of life reporting lower parent-
212 child agreement for children's internalizing problems⁵¹⁻⁵³. These observations were also
213 confirmed here when examining positivity according to cut-points. We noticed that fathers as
214 well as mothers had difficulty inferring the levels or presence of anxiety, depression, and distress
215 of children, especially when these were self-reported by children. This is consistent with a body
216 of literature showing that caregivers identify better the absence (ruling out abilities) than the
217 presence (ruling in) of emotional distress in patients^{39,44,46}. When no distress was reported by
218 children we found that mothers tended to overestimate distress on the more 'subjective' measure
219 (DRS) and more so than fathers, a result that was not observed on more 'objective' measures
220 (BYI), as on the latter, agreements were similar in both parents. Together, these results suggest
221 that mothers could overestimate distress on measures such as thermometers.

222 Moreover, we found no agreement between fathers and children for distress. This does
223 not mean that fathers are less sensitive to children psychological status. They may simply have
224 fewer opportunities to observe their children, may be less open than mothers about psychological
225 issues or have wider estimates of normality⁵⁴. Differences between mothers and fathers in
226 regards to agreements with children report further emphasises the necessity of incorporating
227 mothers' as well as fathers' ratings when approaching the psychological status of young
228 survivors.

229 Our results also show that parents rated higher anxiety, depression and distress for their
230 child than children did to describe their own experience. This observation which could be the

231 result of an overestimation may be the result of strong beliefs about the impact of cancer. Indeed,
232 parents of ill children have held beliefs that an illness causes more negative consequences on the
233 child's status in comparison to other raters⁵⁵. Another possibility is that survivors underestimated
234 their symptoms and difficulties because they believed those were integral parts of their
235 experience. Survivors' ratings may thus not truly reflect their current reality. For example,
236 previous studies have suggested that they sometimes do not fully comprehend the repercussions
237 of their disease^{16,56}. Further, individual differences in psychological functioning such as adaptive
238 style may play a role³³. Children with low anxiety and high repression have been reported to
239 provide lower ratings than their parents on their psychosocial difficulties during cancer
240 treatment. Finally, as time passes, it is possible that judgments on mental quality of life become
241 more normative as a result of an adaptive process, a phenomenon labeled as *response shift*⁵⁷.

242 Exploring potential predictors of parental ratings, our analyses showed that when fathers
243 provided ratings for a girl, or when fathers had lower income, they were prone to overestimate
244 distress. In a similar way, previous studies have identified associations between child's gender,
245 parental income, and rating discrepancies^{58,59}. Of notice, we observed no association between
246 higher child age and larger disagreement as could be expected. Given that most children in our
247 sample were aged between 15-18 years, this may be due to a lack of variability in our sample⁶⁰.
248 We also found that when parents had elevated levels of distress, they tended to overestimate
249 ratings of child anxiety, depression and distress. High distress levels could bias parents' ratings
250 and lead them to overestimate child distress⁶¹. Parents may recall more negative symptoms or
251 negative experiences about their children more so than the children themselves when answering
252 questions on the child status⁶². This phenomenon is all the more important since systematic

253 reviews have reported high levels of parental distress several years after diagnosis in mothers and
254 fathers of children with cancer^{63,64} (although here we found normative distress levels in parents).

255 Notably, the majority of survivors in our study were adolescents aged 15-18 years.

256 Adolescence is a critical developmental period that encompasses emotional, social and
257 behavioral changes intertwined with transitions and increased pressure to be autonomous⁶.

258 Adolescents who have survived childhood cancer face the additional burden of uncertainty about
259 the future and the increased dependency on their parents due to neurocognitive and social
260 impairments^{65,66}. Consequently, communication between survivors and their parents may
261 become even more disrupted, transform into sources of conflict and put a strain on the parent-
262 adolescent relationship^{65,67,68}. In that sense, disagreements observed here may also reflect parent-
263 adolescent relationships⁶⁸. In this adolescent population, accurate evaluation of distress is a
264 major target as teenagers are developing their sense of self and think about their future, the surge
265 of thoughts regarding oneself could enhance the prevalence of internalizing symptoms and
266 comorbidities^{6,69,70}.

267 This study underlines the necessary use of a multi-informant perspective calling for both
268 parents and the child when young survivors are assessed. This allows to gather different pieces of
269 information to optimise the distress identification in older children⁷¹. One possible application
270 could be to use either report in the triad as a valid source of information. Potentially, when one
271 report would be elevated, it could trigger a more thorough assessment of the survivor's
272 psychological status. This work also offers evidence that mothers and fathers evaluate their
273 child's distress differently. Therefore, it is important to consider who within the family informs
274 on the child's status when interpreting results. Finally, as parental mood may impact parental
275 report, a strategy could be to incorporate measures of respondents' distress into questionnaires

276 exploring for child status to control for such factors. This could also serve both purposes of
277 evaluating child and parent status.

278 Some limitations of our study must be acknowledged. Firstly, our findings are contingent
279 upon the experience of well-adjusted survivors and parents as indicated by low levels of distress
280 in families. Our sample is also very homogeneous in terms of ethnic background as well as
281 clinical history (ALL treated with DFCI protocols). This limits the external validity of our
282 results. Secondly, when exploring moderators of agreement, although we controlled for
283 children's self-reports, the cross-sectional design could not warrant that parental psychological
284 symptoms were a causal factor of disagreements between parent's and children's ratings.
285 Thirdly, there was still a large part in disagreement that needed to be explained beyond the
286 factors considered here. Future studies should address other factors that could explain parental
287 ratings of child psychological status. It has recently been suggested that family characteristics,
288 child social desirability and parents' beliefs could influence parental ratings²³ and that a tendency
289 to repress one's feelings could explain underreporting in children³³.

290 To conclude, we studied parental ratings and self-reports of anxiety, depression and
291 distress in 62 triads of mothers, fathers, and older children successfully treated for childhood
292 cancer. We found low levels of agreement on ratings of child distress and showed that larger
293 disagreements were associated with parental psychological symptoms. This study is original as it
294 includes two rarely studied populations, namely older children and adolescents previously treated
295 for pediatric cancer and their fathers. It also notably extends knowledge on distress in pediatric
296 oncology by exploring potential predictors of parental ratings. Future studies should recognize
297 that each rater contributes to our understanding of children distress and extend the exploration of

298 the predictors of parent-child agreement as valid multi-informant assessments of emotional
299 distress are timely in after-care.

300

301 **Conflict of Interest**

302 The authors report no conflicting interests.

303

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Legend

Figure

FIGURE 1 Bland-Altman plots for anxiety, depression and distress comparing children's ratings with their mothers' or father's ratings

Tables

TABLE 1 Sample description (n=62 mother-father-child triads)

TABLE 2 Agreement on child anxiety, depression and distress in 62 mother-father-child triads of children treated for acute lymphoblastic leukemia

TABLE 3 Hierarchical regressions predicting mother and father ratings on children's anxiety, depression and distress

Supplementary file

SUPPLEMENTARY TABLE S1 Agreement between ratings of parent and children on anxiety and depression

SUPPLEMENTARY TABLE S2 Agreement between ratings of parent and children on distress

SUPPLEMENTARY TABLE S3 Agreement between ratings of mothers and fathers on children's anxiety and depression

SUPPLEMENTARY TABLE S4 Agreement between ratings of mothers and fathers on children's distress

SUPPLEMENTARY TABLE S5 Repeatability analysis applied to mother-father differences on ratings of anxiety, depression, and distress of the child

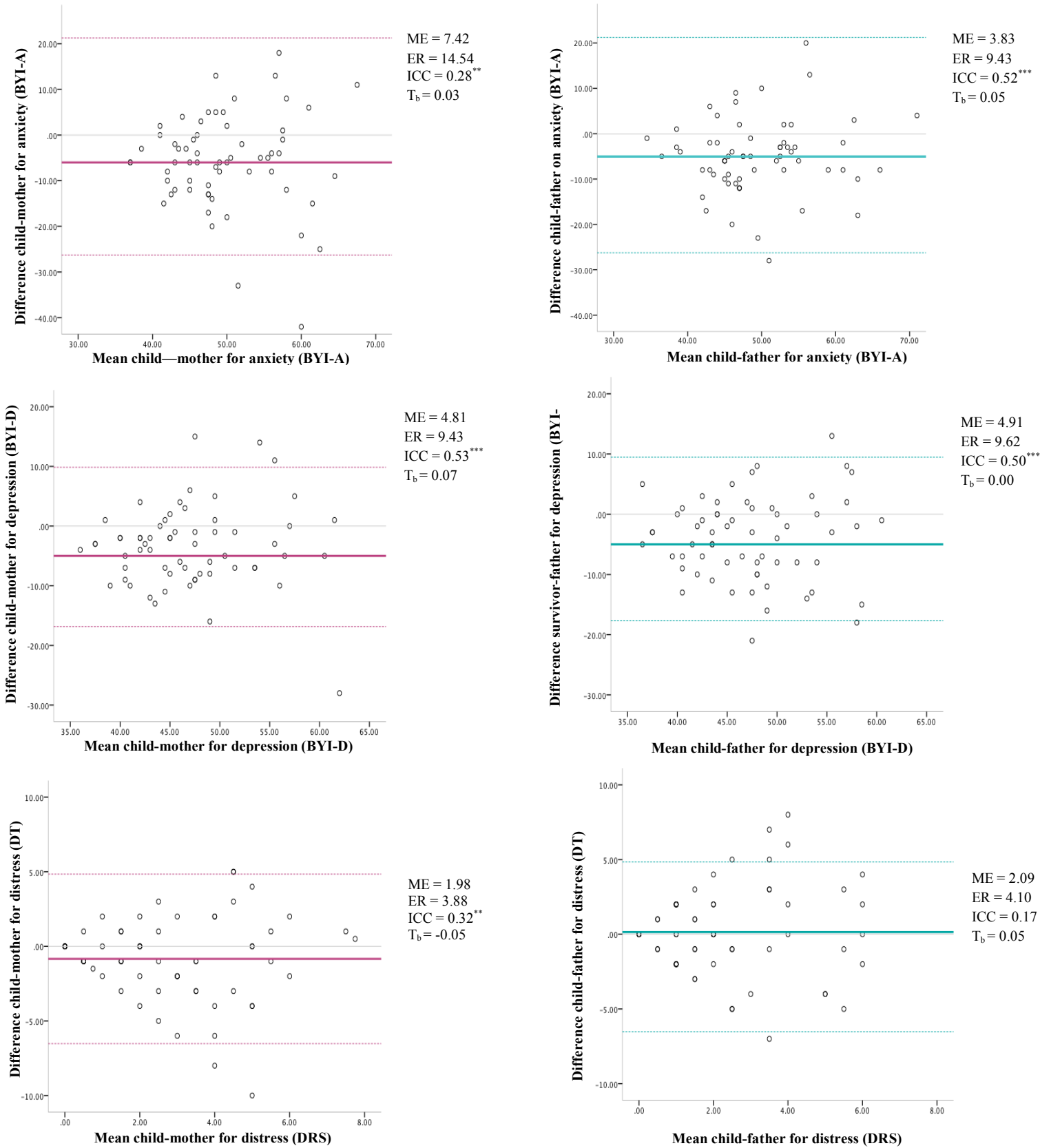
TABLE 1 Sample description (n=62 mother-father-child triads)

Children's characteristics	M (SD) or N (%)	
Age at diagnosis	3.56 (2.19)	
Age at time of study	15.82 (1.92)	
9-12	4	
13-18	58	
Time since diagnosis	11.55 (2.51)	
Sex of child		
Girls	29 (47)	
Boys	33 (53)	
ALL risk status		
Standard risk	34 (55)	
High risk	28 (45)	
Treatment protocol		
DFCI 95-01	16 (26)	
DFCI 00-01	36 (58)	
DFCI 05-01	10 (16)	
Radiation therapy		
No radiation	38 (61)	
Radiation	24 (39)	
Parents' characteristics	Mothers	Fathers
	M (SD) N (%)	M (SD) N (%)
Age at diagnosis	33.69 (5.40)	36.89 (5.40)
Age at time of study	45.24 (5.17)	47.94 (5.03)
Education		
High school	11 (18)	23 (37)
Undergraduate	33 (53)	22 (51)
Graduate	18 (29)	7 (12)
Financial income		
-29,999\$	12 (20)	2 (3)
30-49,999\$	16 (26)	6 (10)
50,000\$-	34 (54)	54 (87)
Marital status		
Same couple as dx	43 (69)	43 (69)
Separated/Divorced	19 (31)	19 (31)
Ethnicity		
Caucasian	61 (98)	62 (100)
Asian	1 (2)	

DFCI: Dana Farber Cancer Institute; dx: diagnosis

Figure 1

Bland-Altman plots for anxiety, depression and distress comparing children's ratings with their mothers' or fathers' ratings



BYI-A: Beck Youth Inventories - anxiety module; BYI-D: Beck Youth Inventories- depression module; DRS: Distress Rating Scale; ME: measurement error; ER: error range; T_b: Kendall's tau. The bold lines indicate the mean of the differences between the dyads and the segmented lines identify the limits of agreement (mean ± 1.96SD).

*p < 0.05

**p < 0.01

***p < 0.001

TABLE 2 Agreement on child anxiety, depression and distress in 62 mother-father-child triads of children treated for acute lymphoblastic leukemia

	Children	Mother-child agreement			Father-child agreement			Mother-Father agreement	
	M (SD)	M (SD)	ICC	t (d)	M (SD)	ICC	t (d)	ICC	t (d)
Children									
Anxiety (BYI-A)	46.87 (8.67)	52.60 (8.82)	0.23*	-4.30***(0.66)	51.92 (8.16)	0.44***	-4.82***(0.60)	0.49***	0.62 (0.08)
Depression (BYI-D)	45.24 (7.03)	48.74 (6.98)	0.47***	-3.06***(0.50)	49.36 (6.89)	0.43***	-4.67***(0.59)	0.37**	-0.62 (0.09)
Distress (DRS)	2.40 (2.37)	3.24 (2.44)	0.31**	5.86*(0.35)	2.26 (2.22)	0.17	-.39 (0.06)	0.16	-2.58**(0.42)

BYI-A: Beck Youth Inventories—anxiety module; BYI-D: Beck Youth Inventories—depression module; DRS: Distress Rating Scale. Effect sizes (d) interpretation: small (.20—.50), medium (.50—.80) and large (.80 or higher) (Cohen, 1988).

*p <0.05

**p <0.01

***p <0.001

TABLE 3 Hierarchical regressions predicting mother and father ratings on children’s anxiety, depression and distress

Predictors	Mothers’ ratings						Fathers’ ratings					
	Anxiety (BYI-A)		Depression (BYI-D)		Distress (DT)		Anxiety (BYI-A)		Depression (BYI-D)		Distress (DRS)	
	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2
Block 1		0.08*		0.28***		0.10**		0.27***		0.25***		0.01
Children’s ratings	0.28*		0.42***		0.24*		0.45***		0.45***		0.16	
Block 2.1												0.23*
Child age	-0.02		0.04		-0.14		0.12		0.11		0.11	
Child sex	0.02		0.13		-0.14		-0.01		-0.03		-0.40**	0.15**
Parental income	-0.10		-0.04		-0.10		-0.05		-0.08		-0.29*	0.08*
Block 2.2			0.10**		0.10**		0.10**		0.10**			
Parental distress	0.23		0.05		0.32**		0.32**		0.32**		0.04	
Parental depression	0.23		0.10		-0.36		-0.19		0.06		-0.01	
Parental anxiety	0.32		0.34**		-0.10		-0.19		-0.18		-0.02	
Parental somatization	0.10		-0.02		0.11		-0.04		0.01		0.02	

BYI-A: Beck Youth Inventories—anxiety module; BYI-D: Beck Youth Inventories—depression module; DRS: Distress Rating Scale

*p <0.05

**p <0.01

***p <0.001

Supplementary Material

SUPPLEMENTARY TABLE S1. Agreement between ratings of parent and children on anxiety and depression

	Mothers' ratings				Fathers' ratings			
	Negative	Positive	Total	% agreement	Negative	Positive	Total	% agreement
Children's ratings:								
Anxiety (BYI-A)								
Negative	36	15	51	71	39	12	51	76
Positive	5	6	11	55	4	7	11	64
Total	41	21	62		43	19	62	
Children's ratings:								
Depression (BYI-D)								
Negative	47	8	55	85	45	10	55	82
Positive	3	4	7	57	4	3	7	43
Total	50	12	62		49	13	62	

Note. BYI-A: Beck Youth Inventories—anxiety module; BYI—D: Beck Youth Inventories—depression module; Negatives refer to scores below T=55. Positives refer to scores of 55 and above (Beck, 2005)

SUPPLEMENTARY TABLE S2. Agreement between ratings of parent and children on distress

	Mothers' ratings				Fathers' ratings			
	Negative	Positive	Total	% agreement	Negative	Positive	Total	% agreement
Children's ratings:								
Distress (DRS)								
Negative	28	18	46	61	38	8	46	83
Positive	8	8	16	50	9	7	16	44
Total	36	26	62		47	15	62	

Note. DRS: Distress Rating Scale. Negatives refer to scores below 4. Positives refer to scores of 4 and above (Boyes, 2013).

SUPPLEMENTARY TABLE S3. Agreement between ratings of mothers and fathers on children’s anxiety and depression

	Mothers’ ratings			% overall agreement
	Negative	Positive	Total	
Fathers’ ratings:				
anxiety (BYI-A)				
Negative	37	6	43	
Positive	4	15	19	
Total	41	21	62	84
Fathers’ ratings:				
depression (BYI-D)				
Negative	43	6	49	
Positive	7	6	13	
Total	50	12	62	79

BYI-A: Beck Youth Inventories—anxiety module; BYI—D: Beck Youth Inventories—depression module; Negatives refer to scores below T=55. Positives refer to scores of 55 and above (Beck, 2005).

SUPPLEMENTARY TABLE S4. Agreement between ratings of mothers and fathers on children’s distress

		Mothers’ ratings			
		Negative	Positive	Total	%
		agreement			
Fathers’ ratings:					
Distress (DRS)					
	Negative	29	18	47	
	Positive	7	8	15	
	Total	36	26	62	60

Note. DRS: Distress Rating Scale. Negatives refer to scores below 4. Positives refer to scores of 4 and above (Boyes, 2013).

SUPPLEMENTARY TABLE S5. Repeatability analysis applied to mother-father differences on ratings of anxiety, depression, and distress of the child

	Lower limit	Upper limit	Mean (SD) of the difference	Measurement error	Error range	Kendall's Tau
Mother-father differences:						
Anxiety (BYI-A)	-16.24	17.59	0.68 (8.63)	6.10	11.96	-0.02
Depression (BYI-D)	-15.90	14.68	0.61 (7.80)	5.52	10.82	-0.07
Distress (DRS)	-4.9	6.86	0.98 (3.00)	2.12	4.16	0.12

BYI-A: Beck Youth Inventories — anxiety module; BYI-D: Beck Youth Inventories — depression module; DRS: Distress Rating Scale