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Parent-Child Agreement on Health-Related Quality of Life Using the PedsQL TM 4.0 in Pediatric Surgery

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Abstract

Purpose

This study examined parent-child agreement (PCA) in health-related quality of life (HRQOL) reports using the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 among pediatric surgery patients, testing agreement across HRQOL dimensions, and examining whether agreement patterns differed according to child age, gender, chronicity, and the reporting parent.

Methods

The study included 5135 parent-child dyads from outpatient pediatric surgery consultations at a German tertiary care center. Participants were aged 8 to 18 years with acute and chronic conditions. Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 was administered via a tablet-based application. Analyses included intraclass correlation coefficients (ICC), linear regression analyses, and Bland-Altman plots to assess agreement and systematic bias.

Results

PCA on HRQOL ranged from moderate to good, with higher agreement for physical functioning and lower for emotional functioning. PCA was higher in chronic than in acute conditions. Emotional functioning showed age- and gender-specific agreement patterns that varied by the reporting parent. During adolescence PCA remained stable in mother-child dyads, increased in father-son dyads and decreased in father-daughter dyads.

Conclusion

Parent-proxy reports of the PedsQL™ should be considered complementary and cannot fully substitute self-reports. Child self-reports remain especially important for assessing emotional functioning, particularly during adolescence, when agreement patterns vary by child gender and the reporting parent.

Introduction

Health-related quality of life (HRQOL) refers to an individual's subjective perception of their physical, mental, and social well-being and daily functioning, including observable and non-observable aspects of health (Hays & Reeve, 2008). HRQOL is commonly assessed using Patient-Reported Outcome Measures (PROMs), including generic, condition-specific, or treatment-specific instruments [1] that can be completed by children or by proxy respondents, such as parents or caregivers. Integrating PROMS into routine pediatric care may improve communication, facilitate the identification of HRQOL-related issues, and potentially improve HRQOL [1]. Assessing HRQOL may also support family-centered care, as a

child's health condition can affect the entire family system [2]. Assessing HRQOL in children is challenging, as developmental changes and situational factors may influence reports over time [3]. Retrospective assessments carry a risk of recall bias, particularly in younger children, who may not accurately remember past symptoms and experiences [3]. When self-reports are not feasible because of physical or cognitive limitations, proxy reports become essential. They may reduce non-response bias by including otherwise underrepresented patient groups in clinical and research settings [4].

Routine HRQOL assessment has been implemented at our institution to complement traditional clinical outcomes and provide a more comprehensive understanding of children's health. As conservative and surgical interventions in pediatric surgery frequently yield comparable clinical outcomes, HRQOL assessment may offer additional insight into treatment benefits from the patient's perspective.

The Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales were selected because they are a generic HRQOL instrument validated for use in healthy children [9] and children with acute and chronic conditions [10], making them well-suited for the heterogeneous population encountered in pediatric surgical outpatient care. It is the most frequently used PROM in pediatric surgery [5] and validated German child self- and parent-proxy report versions are available for the entire age range included in this study.

Parent-proxy reports are often required when self-reports are not feasible. However, evidence regarding the extent, direction, and determinants of PCA remains inconsistent, and it is unclear under which circumstances proxy reports adequately reflect children's HRQOL. Available evidence on parent-child agreement (PCA) is inconsistent, with studies reporting agreement ranging from high to low [6, 7]. When differences occur, proxy respondents often report more problems and reduced functioning than children themselves [4]. Both perspectives are considered valid, as they provide complementary information, with PCA being higher for observable physical aspects of HRQOL and lower for emotional and social domains [6, 8]. Parental psychological distress, depression [9], and poorer parental quality of life [10] have been associated with greater differences in PCA and more negative proxy ratings. Demographic factors may influence PCA, with higher agreement reported in parent-daughter dyads and in Hispanic families [11], whereas lower agreement has been observed in non-Hispanic families [12].

Although the PedsQL is a well-established and widely used instrument for assessing health-related quality of life in children, evidence on PCA remains incomplete, especially in heterogeneous pediatric surgical populations. Prior research suggests that agreement may differ across HRQOL dimensions [6, 8] and vary by child age [6], gender, and the reporting caregiver [10], but these patterns have not been systematically examined in a large outpatient pediatric surgery sample. Therefore, the present study aims to assess the extent of PCA on HRQOL, to examine whether any differences show a systematic direction of bias, and to identify factors associated with variation in agreement across age, gender, disease chronicity, and caregiver type.

Methods

Setting

Between October 2022 and May 2025, questionnaires were administered as part of routine outpatient care to all patients and their parents or guardians attending specialized pediatric surgery consultations (proctology, traumatology, hemangioma, urology, burn, skull and chest wall deformities) at a German university Hospital.

Children with acute conditions completed the PedsQL version referring to the previous seven days, whereas children with chronic conditions completed the version referring to the previous four weeks. Questionnaires were completed on a tablet device in the waiting room before the consultation.

Participants

The present study incorporated a total of 5153 parent-child dyads aged 8 to 18 years. Questionnaires were not administered to children who were unable to complete them independently due to language barriers or physical or cognitive impairments. Exclusion criteria were applied in the following order: missing parent or child questionnaires (*n* = 345), incomplete item responses that prevented score calculation (*n* = 196), technical problems (*n*=31), and cases in which both parent and child reported a total score of 100% (*n* = 137) (see Figure 1).

Measure – The PedsQL 4.0

The PedsQL 4.0 Generic Core Scales were administered electronically via tablet as part of routine clinical HRQOL assessment. Participants could skip individual questions or decline to complete the questionnaire. The questionnaire comprises 23 items assessing physical, emotional, social, and school functioning, from which a Total Score, a Physical Health Score, and a Psychosocial Health Score are derived. Items are rated on a 5-point Likert scale ranging from 0 (“Never a problem”) to 4 (“Almost always a problem”) and transformed to a 0-100 scale, with higher scores indicating better HRQOL.

Statistical analysis

Statistical analyses were performed using SPSS 29.0.2.0, Apache Superset, and Python 3.13. Agreement was first examined in the total sample, including mother, father, and other caregiver reports as well as children with diverse or unspecified gender. For consistency with prior literature, the term *parent-child agreement* is used throughout this manuscript, although other caregivers also provided some proxy reports. Analyses were stratified by age group, disease chronicity, caregiver type, and child gender (Table 1).

Table 1 Sample characteristics

Characteristic	Category	N (%) [a]
Total sample	Parent-child dyads	5153 (100)
Gender	Male	3130 (60.74)
	Female	2012 (39.05)
	Diverse/not specified [b]	11 (0.21)
Caregiver	Mother	3361 (65.22)
	Father	1471 (28.55)
	Other caregiver [c]	321 (6.23)
Age group	8-12 years	3096 (60.08)
	13-18 years	2057 (39.92)
Chronicity	Acute	4033 (78.27)
	Chronic	1120 (21.73)

[a] Values are presented as n (%) of the total sample.
[b] Children with diverse or unspecified genders were combined into a single category.
[c] Other caregiver includes all proxy respondents other than mothers and fathers.

More detailed subgroup analyses combining age group, chronicity, and parent and child gender were restricted to dyads with mother or father proxy reports and to children of male or female gender due to the small number and heterogeneity of the excluded cases (Table 2).

Table 2 Distribution of participants across subgroup combinations

Chronicity	Age group	Mother-girl dyads, *n* (%)	Mother-boy dyads, *n* (%)	Father-girl dyads, *n* (%)	Father-boy dyads, *n* (%)
Acute	8-12 years	685 (14.21)	897 (18.60)	300 (6.22)	440 (9.12)
	13-18 years	390 (8.09)	600 (12.44)	165 (3.42)	292 (6.06)
Chronic	8-12 years	157 (3.26)	267 (5.54)	49 (1.02)	106 (2.20)
	13-18 years	122 (2.53)	233 (4.83)	31 (0.64)	88 (1.82)

Values are presented as *n* (%) of the analytic sample. Children with diverse or unspecified gender and caregivers other than the mother or father were excluded from subgroup analyses due to too small sample sizes.

Agreement was assessed using the Intraclass Correlation Coefficient (ICC) at the score and item level separately within each predefined subgroup. ICCs were calculated using a two-way mixed-effects model for absolute agreement and single measurements (ICC(3,1)), as each parent-child dyad represented a fixed pair of raters and the aim was to evaluate absolute agreement. ICCs were interpreted according to Koo and Li [13], with values below .50 indicating poor, .50 -.75 moderate, .75-.90 good, and above .90 excellent agreement. Due to a technical issue during the transfer of tablet-based questionnaire data to the electronic patient records, responses to item 113 (“I was angry”) were missing for all participants completing the chronic questionnaire version and for a subset of participants completing the acute version, preventing ICC calculation for this item in these participants.

Absolute difference scores were calculated for each scale, with higher values indicating greater discrepancies. Directed difference scores were calculated by subtracting child self-report scores from parent-proxy report scores, with positive values indicating higher parent ratings and negative values indicating higher child ratings. To compare whether agreement differed between parents and other caregivers, mothers and fathers were combined into a single parent group and compared with other caregivers using Welch’s *t*-test based on absolute difference scores. Full-factorial linear regression models, including age group, child gender, disease chronicity, and reporting parent, were calculated for each questionnaire dimension to examine the independent and interactive effects of these variables on PCA. Significant interaction effects were further explored using model-based simple effects analyses, examining age-group differences within each parent-child subgroup. To account for multiple testing across the four simple effects, *p*-values were adjusted using Bonferroni correction, and the adjusted *p*-

values are reported throughout. Bland-Altman Plots were used to assess possible systematic bias between parent and child ratings and to evaluate the limits of agreement across the measurement range.

Results

Descriptive statistics

Overall, 5153 parent-child dyads were analyzed, consisting of 4003 acute pairs and 1120 chronic questionnaire pairs. The sample comprised 3130 boys, 2012 girls, and 11 children with a diverse or unspecified gender, with 3096 children aged 8-12 years and 2057 aged 13-18 years. Most proxy reports were completed by mothers (*n* = 3361), followed by fathers (*n* = 1471) and other caregivers (*n* = 321).

Parent-child agreement across HRQOL dimensions

ICCs indicated moderate to good agreement between parent-proxy and child self-reports across all HRQOL scales, ranging from .63 for emotional functioning to .89 for physical functioning (Table 3). The Total Score showed good agreement between parent and child ratings (ICC = .71, 95% CI [.70, .73]). Mean absolute parent-child difference for the total HRQOL score was 8.16 points (*SD* = 8.82), whereas the directed mean difference indicated slightly lower parent ratings compared to child self-reports (*M* = -2.17, *SD* = 11.82).

As shown in Table 2, agreement differed across HRQOL dimensions. Physical functioning showed the highest agreement (ICC = .89, 95% CI [.88, .89]), and smaller absolute differences (*M* = 7.46, *SD* = 9.08), whereas emotional functioning showed the lowest agreement (ICC = .63, 95% CI [.61, .64]) and the largest absolute differences (*M* = 11.43, *SD* = 11.81). A paired-samples *t*-test confirmed that absolute differences were significantly larger for emotional than for physical functioning (t (5152) = 21.09, p < .001, d = 0.38). Directed mean differences indicated that parents tended to rate children's emotional HRQOL lower than the children themselves (*M* = -3.99, *SD* = 15.94). Social functioning (ICC = .72) and school functioning (ICC = .78) showed moderate agreement (Table 3).

Table 3 Intraclass correlations between child and caregiver ratings for HRQOL scale scores

Scale	Child *M* (*SD*)	Caregiver *M* (*SD*)	*M* abs. diff. [a] (*SD*)	*M* diff. [b] (*SD*)	ICC [95 % CI][c]
Total HRQOL	79.3 (15.35)	77.13 (15.96)	8.16 (8.82)	-2.17 (11.82)	.71 [.70, .73]
Physical	73.25 (23.62)	71.62 (25.13)	7.46 (9.08)	-1.62 (11.64)	.89 [.88, .89]
Emotional	81.25 (18.18)	77.27 (18.8)	11.43 (11.81)	-3.99 (15.94)	.63 [.61, .64]
Social	86.7 (15.59)	85.09 (16.38)	7.39 (9.43)	-1.61 (11.87)	.72 [.71, .74]
School	79.16 (18.73)	77.86 (18.94)	8.1 (9.72)	-1.3 (12.59)	.78 [.77, .79]

Item-specific parent-child agreement

As shown in Table 4, item-specific ICCs demonstrated predominantly moderate to good agreement between parent-proxy and child self-reports, with ICC values ranging from .45 to .85. Consistent with the score-level analysis, physical functioning items showed the highest agreement (ICC range = .66 - .85), whereas emotional items showed the lowest agreement (ICC range = .45 - .68). Item 113 (“I was angry”) was the only item with poor agreement and showed the lowest ICC across the questionnaire (ICC = .45, 95% CI [.42, .47]) the largest absolute difference (*M* = 0.63, *SD* = 0.81) and the largest directed difference (*M* = 0.35, *SD*= 0.96). As responses to this item affected by the above-mentioned data transfer issue were treated as missing, the reported ICC was based exclusively on the remaining valid acute questionnaire sample, which still comprised 3916 parent-child dyads. Across most items, directed mean differences were small, indicating only minor systematic differences between parent and child ratings. Unlike the transformed scale scores, item-level analyses were based on the original response scale, thereby reversing the interpretation of directed differences: positive directed differences indicate greater symptom burden reported by parents and, therefore, lower parent-reported HRQOL.

Table 4 Intraclass correlations between child and caregiver ratings of HRQOL by item

Item	*N* [a]	Child *M* (*SD*)	Caregiver *M* (*SD*)	*M* abs. diff. [b] (*SD*)	*M* diff.[c] (*SD*)	ICC [d] [95 % CI]
Physical						
011 Walking	5104	0.56 (1.12)	0.56 (1.13)	0.25 (0.6)	0.0 (0.65)	.83 [.83, .84]
012 Running	5087	1.23 (1.52)	1.23 (1.56)	0.39 (0.74)	-0.01 (0.84)	.85 [.84, .86]
013 Exercise	5083	1.67 (1.56)	1.8 (1.63)	0.51 (0.83)	0.12 (0.97)	.82 [.81, .83]
014 Lifting	5088	1.08 (1.3)	1.21 (1.44)	0.51 (0.8)	0.13 (0.94)	.77 [.76, .78]
015 Daily hygiene	5088	0.93 (1.44)	1.03 (1.51)	0.33 (0.74)	0.1 (0.81)	.85 [.84, .86]
016 Chores	5086	0.98 (1.25)	1.09 (1.32)	0.5 (0.77)	0.11 (0.91)	.75 [.74, .76]
017 Pain	5096	1.23 (1.13)	1.26 (1.12)	0.46 (0.65)	0.03 (0.8)	.75 [.74, .76]
018 Fatigue	5084	0.85 (1.01)	0.91 (1.01)	0.48 (0.68)	0.05 (0.83)	.66 [.65, .68]
Emotional						
111 Fear	5099	0.7 (0.96)	0.78 (0.95)	0.43 (0.65)	0.08 (0.77)	.67 [.66, .69]
112 Sadness	5098	0.83 (0.97)	0.96 (0.96)	0.47 (0.66)	0.13 (0.8)	.66 [.64, .67]
113 [e] Anger	3916	0.57 (0.89)	0.92 (0.94)	0.63 (0.81)	0.35 (0.96)	.45 [.42, .47]
114 Sleep	5098	0.83 (1.05)	0.82 (0.98)	0.45 (0.69)	-0.01 (0.83)	.67 [.65, .68]
115 Worry	5087	0.85 (1.08)	0.98 (1.06)	0.51 (0.71)	0.13 (0.86)	.68 [.66, .69]
Social						
211 Peer conflicts	5094	0.35 (0.72)	0.43 (0.75)	0.34 (0.61)	0.09 (0.7)	.55 [.53, .57]
212 Friendships	5094	0.27 (0.66)	0.34 (0.7)	0.28 (0.57)	0.08 (0.63)	.57 [.55, .58]

213 Being teased	5094	0.3 (0.71)	0.36 (0.71)	0.24 (0.54)	0.06 (0.58)	.66 [.64, .67]
214 Keeping up	5096	0.98 (1.21)	1.03 (1.26)	0.54 (0.8)	0.04 (0.97)	.69 [.68, .71]
215 Play participation	5083	0.75 (1.1)	0.81 (1.12)	0.51 (0.79)	0.05 (0.94)	.65 [.63, .66]
School						
311 Focusing	5085	0.71 (0.98)	0.76 (0.99)	0.45 (0.7)	0.05 (0.83)	.64 [.63, .66]
312 Memory	5090	0.88 (0.97)	0.97 (0.98)	0.47 (0.68)	0.09 (0.82)	.65 [.63, .66]
313 Schoolwork	5086	0.78 (0.99)	0.9 (1.02)	0.52 (0.73)	0.12 (0.89)	.61 [.59, .62]
314 Absence (illness)	5091	0.8 (1.1)	0.8 (1.08)	0.36 (0.66)	0.0 (0.75)	.76 [.75, .77]
315 Absence (medical)	5092	0.99 (1.06)	1.0 (1.06)	0.37 (0.66)	0.0 (0.76)	.74 [.73, .76]

[a] *N* varies by item due to missing data; only complete parent-child dyads for the respective item were included.

[b] *M* abs. diff. = absolute parent-child difference.

[c] *M* diff. = directed parent-child difference (parent minus child).

[d] ICCs are reported as two-way mixed-effects, single-measure, absolute-agreement coefficients (ICC(3,1)) with 95% CI.

[e] For item 113, responses affected by a technical data transfer issue were treated as missing before analysis.

Parent-child agreement according to chronicity and caregiver

Item-level agreement patterns across subgroups are illustrated in Figure 2. Although agreement varied between items and subgroups, physical functioning items consistently demonstrated higher agreement, whereas emotional items tended to show lower agreement and greater variability. Agreement was higher in chronically ill children than in children with acute conditions, as reflected by smaller absolute differences between parent and child reports ($M^{chronic}$ = 6.44, *SD* = 6.83; M^{acute} = 8.64, *SD* = 9.25; $t(2376.85) = 8.78$, $p < .001$, $d = 0.25$). Directed mean differences were almost identical in acute and chronic conditions ($M^{chronic}$ = -2.19, *SD* = 9.13; M^{acute} = -2.16, *SD* = 12.47; $t(2400.24) = 0.08$, $p = .933$, $d = 0.002$). Negative mean differences in both groups indicated that parents tended to rate their children's

HRQOL lower than the children themselves. The higher agreement observed in chronically ill individuals, therefore, appears unrelated to systematic differences in rating direction and may instead reflect more consistent parent-child ratings in chronic conditions.

Welch's *t*-test based on absolute differences revealed no significant differences between parents and other caregivers for any HRQOL scale (all $p > .16$, all $d < 0.08$, all 95% CIs for the mean differences included zero), indicating comparable agreement across caregiver groups. Absolute differences were nearly identical for physical functioning ($M^{parent} = 7.46$, $SD = 9.07$; $M^{caregiver} = 7.54$, $SD = 9.19$) and emotional functioning ($M^{parent} = 11.45$, $SD = 11.45$; $M^{caregiver} = 11.22$, $SD = 12.22$).

Bland-Altman analysis

Bland-Altman plots for physical (Figure 3A) and emotional functioning (Figure 3B) showed small systematic differences between parent and child ratings ($M^{physical}$ =-1.62, $SD = 11.64$; $M^{emotional} = -3.99$, $SD = 15.94$). Limits of agreement were wider for emotional functioning than for physical functioning (-35.24 to 27.27 vs. -24.44 to 21.19), indicating greater variability in parent-child differences for emotional aspects of HRQOL. Both plots showed a funnel-shaped pattern, indicating higher PCA at higher HRQOL levels and increasing variability in agreement as HRQOL decreased.

Factors associated with parent-child agreement

To further examine subgroup differences in agreement, linear regression analyses were conducted in a subsample of 4822 dyads with mother- or father-proxy reports and children with male or female gender, including age group, child gender, chronicity, and reporting parent as predictors of PCA across HRQOL dimensions. The models explained only a small proportion of variance in agreement (R^2 = .005-.017). Chronicity was associated with significantly smaller differences for the Total Score ($F(1, 4806) = 30.46$, $p < .001$, $\eta^2 = .006$) and physical functioning ($F(1, 4806) = 24.92$, $p < .001$, $\eta^2 = .005$). Emotional functioning showed a significant three-way interaction among age, reporting parent, and child gender ($F(1, 4806) = 13.28$, $p < .001$, $\eta^2 = .003$).

Given the significant three-way interaction, model-based simple effects analyses with Bonferroni-corrected pairwise comparisons were conducted. Estimated marginal means (EMMs) indicated that for mother reports, parent-child differences showed a small numerical decrease with age for boys ($EMM^{8\text{-}12\ years} = 12.43$, $SE = 0.41$, 95% CI [11.63, 13.24]; $EMM^{13\text{-}18\ years} = 11.01$, $SE = 0.45$, 95% CI [10.12, 11.90]), although this difference did not remain statistically significant after Bonferroni correction ($t(4806) = 2.34$, adjusted $p = .078$, $d = 0.12$). No age-related differences were observed for girls ($EMM^{8\text{-}12\ years} = 11.46$, $SE = 0.52$, 95% CI [10.44, 12.47]; $EMM^{13\text{-}18\ years} = 11.13$, $SE = 0.61$, 95% CI [9.94, 12.32]; $t(4806) = 0.41$, adjusted $p = 1.000$, $d = 0.03$). For father reports, differences decreased with age for boys ($EMM^{8\text{-}12years} = 11.56$, $SE = 0.63$, 95% CI [10.31, 12.80]; $EMM^{13\text{-}18years} = 8.31$, $SE = 0.71$, 95% CI [6.91, 9.70]; $t(4806) =$

3.41, adjusted p = .003, d = 0.28) but increased with age for girls ($EMM^{8\text{-}12years}$ = 9.26, SE = 0.90, 95% CI [7.49, 11.03]; $EMM^{13\text{-}18years}$ = 14.45, SE = 1.15, 95% CI [12.20, 16.70]; $t(4806)$ = -3.55, adjusted p = .002, d = -0.44), with adolescent father-daughter dyads showing the numerically highest estimated marginal mean among all subgroups. The interaction pattern is illustrated in Figure 4.

Discussion

Parent-Child Agreement Across HRQOL Dimensions and Subgroups

The study demonstrated overall moderate to good agreement between parent-proxy and child self-reports of HRQOL in a large pediatric surgical outpatient sample. Previous studies have reported agreement levels ranging from low to good across different populations and HRQOL domains [7], placing the present findings within the range of existing evidence. One of the main findings was the variation in agreement across HRQOL dimensions. PCA was consistently higher for physical functioning than for emotional functioning, consistent with previous studies [6, 14]. This pattern is likely related to the different observability of these domains, as emotional well-being is less directly observable than physical impairment and depends more strongly on explicit parent-child communication. Accurate parental assessment of emotional functioning may require children to actively express emotional distress. In the present study, parents tended to rate their children's emotional functioning lower than the children themselves, indicating greater perceived emotional impairment. Previous studies have reported inconsistent findings regarding the direction of parent-child differences in emotional functioning, with some studies reporting higher symptom ratings among children [17, 18] and others reporting higher parental ratings, particularly in clinical populations [4, 15].

Although no pronounced systematic bias was observed overall, PCA varied considerably across individual dyads and across HRQOL dimensions. This indicates that parent-proxy reports may provide a reasonable approximation of HRQOL at the group level, while individual ratings can differ, particularly in emotional dimensions.

Beyond dimension-specific differences, the present study identified factors associated with variations in agreement. Agreement was higher among children with chronic conditions than among those with acute conditions. This may reflect longer disease duration, greater parental involvement, and more frequent communication about symptoms and limitations in everyday life. Over time, children may increasingly perceive illness as part of everyday life, while parents become more familiar with their child's condition. This interpretation is consistent with Pinquart's [16] meta-analytic finding that most families adapt well to a child's chronic illness and establish parent-child relationships comparable to those in families with healthy children. Qualitative interviews suggested that chronic illness may strengthen family relationships in some families [17], potentially enhancing understanding and communication and contributing to higher PCA. In contrast, parents of children with acute illnesses often report uncertainty and difficulties understanding their child's condition [18], which may impair their ability to accurately assess their child's HRQOL and contribute to the lower agreement observed in the present study.

Previous studies have reported inconsistent findings regarding the association between chronicity and PCA. While higher agreement has been observed in chronically ill children compared with healthy children [14], chronic illness was not associated with PCA in another study [19]. Differences in study populations, comparison groups, and HRQOL dimensions may explain these discrepant findings, as studies did not directly compare acute and chronic conditions.

Age-related patterns of PCA in emotional functioning varied by child gender and the reporting parent: While PCA remained stable in mother-child dyads, it increased with age in father-son dyads and decreased in father-daughter dyads. The lower agreement observed in father reports for younger boys and older girls may be related to age- and gender-specific differences in perceived and actual paternal availability. Liebermann et al. [20] found that younger boys and older girls perceive their fathers as less available than their mothers, while adolescent girls additionally report being less dependent on their fathers. Adolescents generally report decreasing levels of parental closeness and intimacy, and relationships with fathers have been characterized by less frequent communication and lower perceived emotional support compared with relationships with mothers [21]. These differences may contribute to the increasing differences between fathers and daughters observed in the present study. Evidence from clinical samples further suggests that father-daughter communication may be affected in the presence of emotional difficulties, as girls diagnosed with depression reported poorer communication and reduced paternal emotional availability [22]. In addition, mothers and daughters may share more gender-specific experiences and concerns during adolescence, potentially facilitating communication about emotionally relevant topics. Similarly, adolescent girls have been shown to seek advice about sexual health more often from their mothers than from their fathers [23], suggesting that emotionally relevant concerns arising during puberty may be discussed more frequently with mothers. During adolescence, girls become more attached to peers than boys, and their friendships are characterized by greater emotional disclosure [24]. Emotional concerns may therefore increasingly be discussed with friends rather than parents, potentially contributing to the declining agreement observed in father reports of older girls. At the same time, mothers may remain more involved in discussions about emotional well-being. In boys, emotional PCA remained stable with age in mother-son dyads and decreased in father-son dyads. Boys' peer relationships have been characterized more by shared activities rather than emotional disclosure [25]. If emotional concerns continue to be discussed primarily within the family, parents may retain better access to information about their son's emotional well-being, which may help explain the trend towards smaller parent-child differences observed among older boys.
Traditional caregiving roles may also influence differences in father-child agreement on emotional HRQOL. In many families, fathers remain more engaged in paid employment and less involved in everyday caregiving, potentially reducing opportunities for routine health-related communication. Consistent with this interpretation, more than twice as many children in our sample were accompanied by their mothers to outpatient consultations.

Although significant subgroup differences were identified, the observed effect sizes were small and only a limited proportion of variance in PCA was explained (R^2 = .004–.016). Additional factors, including disease severity, family functioning, parental mental health, and socioeconomic status, may also

influence agreement. Rather than identifying the strongest determinants of agreement, the present study focused on clinically relevant and readily assessable subgroup characteristics to explore whether agreement differed between subgroups.

Clinical importance and Research implications

Integrating PROMs into routine clinical practice may contribute to more comprehensive pediatric surgical care. The present findings highlight the importance of incorporating both children's and parents' perspectives into HRQOL assessments, particularly for emotional functioning, which is often insufficiently captured by conventional diagnostic procedures used in pediatric surgery.

Parent-proxy reports provide valuable complementary information, particularly when children are very young or unable to complete questionnaires independently [26]. In clinical practice and research, proxy assessments may facilitate the inclusion of patient groups that would otherwise be underrepresented in HRQOL assessments [5], thereby contributing to a more inclusive evaluation of treatment outcomes and patient experiences. However, previous longitudinal research suggests that child self-reports should be prioritized whenever possible, particularly in non-severely affected pediatric populations, as parent and child perspectives are considered complementary rather than interchangeable, and individual-level agreement may remain limited [27].

Rather than solely reflecting measurement error, differences between parent and child reports may provide clinically meaningful information, as parents and children rely on different sources when evaluating HRQOL. Children have direct access to subjective experiences, whereas parents rely primarily on observable behaviors and parent-child communication [28]. In the present study, emotional functioning showed the lowest PCA, and parents rated children’s emotional functioning lower than children themselves. Similar discrepancies have been associated with poorer treatment outcomes in pediatric mental health settings [15], suggesting that parent-child differences may be relevant not only to assessment and diagnosis but also to treatment outcomes. As parent-proxy reports and child self-reports provide complementary rather than interchangeable perspectives on children’s HRQOL [29], diverging perceptions of HRQOL may reflect unmet emotional needs, differences in symptom perception, or challenges in parent-child communication and may therefore warrant additional clinical attention.

Strengths and limitations

The present study includes a large, heterogeneous sample of children with acute and chronic conditions who were treated in routine pediatric surgery outpatient care. In contrast to previous studies focusing on specific diseases, the broad spectrum of conditions included in our study may increase the generalizability of the findings to other pediatric populations. However, the heterogeneity of the sample limits conclusions regarding agreement patterns in specific diagnostic groups.

In contrast to previous studies combining parent-proxy reports into a single category, the present study differentiated between mother and father reports, enabling the identification of agreement patterns across family subgroups. However, mothers were overrepresented, limiting the interpretability of father-specific findings. Although other caregivers were included in additional analyses, this heterogeneous group remained comparatively small, limiting a more detailed examination of agreement patterns.

Due to language barriers and some children's inability to complete the questionnaires independently, certain patient groups were not represented in the present study, potentially limiting the inclusivity and generalizability of the findings. The absence of detailed sociodemographic and psychosocial variables further limits the interpretation of factors influencing PCA. Future studies may benefit from more inclusive multilingual assessment approaches, broader representation of caregiver and gender identities, and additional sociodemographic and clinical variables. Longitudinal studies are also needed to examine whether PCA is associated with treatment engagement and outcomes.

Conclusion

Parent-proxy and child self-reports of HRQOL demonstrated moderate to good agreement in pediatric surgical outpatients. Agreement was highest for physical functioning and lowest for emotional functioning, with parents tending to report poorer emotional HRQOL than children themselves. Chronic conditions were associated with higher PCA, whereas PCA in emotional functioning varied by child age, gender, and the reporting parent. PCA remained stable with age in mother-child dyads irrespective of child gender, whereas father-child dyads, PCA increased with age among boys but decreased among girls. These findings suggest that parent-proxy and child self-reports should be considered complementary rather than interchangeable sources of information. Nevertheless, proxy reports may provide a reasonable approximation of children’s HRQOL when self-reports are not feasible, particularly for observable physical aspects of functioning. Their interpretation should, however, consider subgroup-specific differences in agreement. Clinicians should therefore consider the child’s age, gender, and the reporting parent when interpreting HRQOL assessments, particularly for emotional functioning during adolescence.

Declarations

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Competing interest

The authors have no relevant financial or non-financial competing interest to disclose.

Author Contributions

All authors contributed to the conception and design of the study. Material preparation, literature review, and data collection were performed by Henrike Weiß and Pia Elshof. Henrike Weiß performed the statistical analyses, created the data visualization, and wrote the first draft of the manuscript. Pia Elshof made substantial contributions to the literature review, data verification, and critical revision of the manuscript. Hannah Stolzenburg contributed to the identification and selection of the final study population and assisted in the data visualizations. Luise Donat was responsible for the preparation and revision of the raw dataset. Christina Pählig provided statistical advice, contributed to the interpretation of the results, and critically revised the manuscript. Guido Fitze contributed to the conception of the study and provided scientific supervision throughout the project. Jurek Schultz made major contributions to the conception and design of the study, led the pediatric HRQOL research group, supervised the implementation of the routine HRQOL assessment, critically revised the manuscript, and served as the primary contact with James W. Varni and MAPI Research Trust regarding the use of the PedsQL questionnaire. Isabel Alkhasli provided overall supervision of the project, contributed to the statistical and methodological interpretation of the results, and critically revised the manuscript. All authors read and approved the final manuscript.

Ethics approval

The retrospective anonymous analysis and reporting of the presented data was approved by the Ethics Committee of the Technical University Dresden (EK433102016). The study was conducted in accordance with the principles of the Declaration of Helsinki.

Consent to participate

Written informed consent was waived because this study used only retrospectively collected routine clinical data. However, all patients and caregivers were free to decline to complete any questionnaires or specific items. Data were analyzed in anonymized form within the established data governance framework.

Consent to publish

No identifiable individual participant data, images, or personal details are included in this manuscript; therefore, publication consent was not required.

References

1. Bele, S., Chugh, A., Mohamed, B., Teela, L., Haverman, L., & Santana, M. J. (2020). Patient-Reported Outcome Measures in Routine Pediatric Clinical Care: A Systematic Review. *Frontiers in Pediatrics*, *8*, 364. https://doi.org/10.3389/fped.2020.00364
2. Witt, S., Dellenmark-Blom, M., Dingemann, J., Dingemann, C., Ure, B. M., Gomez, B., & Quitmann, J. (2019). Quality of Life in Parents of Children Born with Esophageal Atresia. *European Journal of Pediatric Surgery*, *29*(04), 371–377. https://doi.org/10.1055/s-0038-1660867
3. Fraser, H., Thompson, L., Crawley, E., Ridd, M. J., & Brigden, A. (2024). not one size fits all The challenges of measuring paediatric health-related quality of life and the potential role of digital ecological momentary assessment: a qualitative study. *Quality of Life Research*, *33*(2), 443–452. https://doi.org/10.1007/s11136-023-03535-6
4. Essen, L. V. (2004). Proxy ratings of patient quality of life Factors related to patient–proxy agreement. *Acta Oncologica*, *43*(3), 229–234. https://doi.org/10.1080/02841860410029357
5. Spivack, O. K. C., Dellenmark-Blom, M., Dingemann, J., Kate, C. A., ten, Wallace, V., Bramer, W. M., & Rietman, A. (2024). A Narrative Review of Patient-Reported Outcome Measures and Their Application in Recent Pediatric Surgical Research: Advancing Knowledge and Offering New Perspectives to the Field. *European Journal of Pediatric Surgery*, *34*(2), 143–161. https://doi.org/10.1055/s-0043-1778108
6. Cremeens, J., Eiser, C., & Blades, M. (2006). Factors influencing agreement between child self-report and parent proxy-reports on the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™) generic core scales. *Health and Quality of Life Outcomes*, *4*, 58. https://doi.org/10.1186/1477-7525-4-58
7. Quitmann, J., Rohenkohl, A., Sommer, R., Bullinger, M., & Silva, N. (2016). Explaining parent-child (dis)agreement in generic and short stature-specific health-related quality of life reports: do family and social relationships matter? *Health and Quality of Life Outcomes*, *14*, 150. https://doi.org/10.1186/s12955-016-0553-0
8. Robitail, S., Siméoni, M. C., Ravens-Sieberer, U., Bruil, J., & Auquier, P. (2007). Children proxies' quality-of-life agreement depended on the country using the European KIDSCREEN-52 questionnaire. *Journal of Clinical Epidemiology*, *60*(5), 469. https://doi.org/10.1016/j.jclinepi.2006.09.007. .e1-469.e13
9. Löchner, J., Hämmerle, S., Ghezih, S., Starman-Wöhrle, K., Schulte-Körne, G., & Platt, B. (2024). Parent-child agreement on children's psychopathology and the impact of parental depression. *International Journal of Methods in Psychiatric Research*, *33*(1), e1993. https://doi.org/10.1002/mpr.1993
10. Witt, S., Kolb, B., Bloemeke, J., Mohnike, K., Bullinger, M., & Quitmann, J. (2019). Quality of life of children with achondroplasia and their parents - a German cross-sectional study. *Orphanet Journal of Rare Diseases*, *14*, 194. https://doi.org/10.1186/s13023-019-1171-9
11. Carlston, D. L., & Ogles, B. M. (2009). Age, Gender, and Ethnicity Effects on Parent–Child Discrepancy Using Identical Item Measures. *Journal of Child and Family Studies*, *18*(2), 125–135. https://doi.org/10.1007/s10826-008-9213-2

12. Ochoa-Dominguez, C. Y., Hamilton, A. S., Zhuang, X., Mack, W. J., & Milam, J. E. (2024). Factors Associated With Agreement Between Parent and Childhood Cancer Survivor Reports on Child's Health Related Quality of Life. *Evaluation & the Health Professions*, *47*(3), 328–335. https://doi.org/10.1177/01632787231185856
13. Koo, T. K., & Li, M. Y. (2016). A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research. *Journal of Chiropractic Medicine*, *15*(2), 155–163. https://doi.org/10.1016/j.jcm.2016.02.012
14. Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research*, *10*(4), 347–357. https://doi.org/10.1023/A:1012253723272
15. Goolsby, J., Rich, B. A., Hinnant, B., Habayeb, S., Berghorst, L., De Los Reyes, A., & Alvord, M. K. (2018). Parent–Child Informant Discrepancy is Associated with Poorer Treatment Outcome. *Journal of Child and Family Studies*, *27*(4), 1228–1241. https://doi.org/10.1007/s10826-017-0946-7
16. Pinquart, M. (2013). Do the Parent–Child Relationship and Parenting Behaviors Differ Between Families With a Child With and Without Chronic Illness? A Meta-Analysis. *Journal of Pediatric Psychology*, *38*(7), 708–721. https://doi.org/10.1093/jpepsy/jst020
17. Sloper, P. (2000). Predictors of Distress in Parents of Children With Cancer: A Prospective Study. *Journal of Pediatric Psychology*, *25*(2), 79–91. https://doi.org/10.1093/jpepsy/25.2.79
18. Kai, J. (1996). Parents' difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *Bmj*, *313*(7063), 987–990. https://doi.org/10.1136/bmj.313.7063.987
19. Theunissen*, N. C. M., Vogels, T. G. C., Koopman, H. M., Verrips, G. H. W., Zwinderman, K. A. H., Verloove-Vanhorick, S. P., & Wit, J. M. (1998). The proxy problem: child report versus parent report in health-related quality of life research. *Quality of Life Research*, *7*(5), 387–397. https://doi.org/10.1023/A:1008801802877
20. Lieberman, M., Doyle, A. B., & Markiewicz, D. (1999). Developmental Patterns in Security of Attachment to Mother and Father in Late Childhood and Early Adolescence: Associations with Peer Relations. *Child Development*, *70*(1), 202–213.
21. Bosco, G. L., Renk, K., Dinger, T. M., Epstein, M. K., & Phares, V. (2003). The connections between adolescents' perceptions of parents, parental psychological symptoms, and adolescent functioning. *Journal of Applied Developmental Psychology*, *24*(2), 179–200. https://doi.org/10.1016/S0193-3973(03)00044-3
22. Demidenko, N., Manion, I., & Lee, C. M. (2015). Father–Daughter Attachment and Communication in Depressed and Nondepressed Adolescent Girls. *Journal of Child and Family Studies*, *24*(6), 1727–1734. https://doi.org/10.1007/s10826-014-9976-6
23. Ogle, S., Glasier, A., & Riley, S. C. (2008). Communication between parents and their children about sexual health. *Contraception*, *77*(4), 283–288. https://doi.org/10.1016/j.contraception.2007.12.003
24. Gorrese, A., & Ruggieri, R. (2012). Peer Attachment: A Meta-analytic Review of Gender and Age Differences and Associations with Parent Attachment. *Journal of Youth and Adolescence*, *41*(5),

650–672. https://doi.org/10.1007/s10964-012-9759-6

25. Rose, A. J., & Rudolph, K. D. (2006). A review of sex differences in peer relationship processes: Potential trade-offs for the emotional and behavioral development of girls and boys. *Psychological Bulletin*, *132*(1), 98–131. https://doi.org/10.1037/0033-2909.132.1.98
26. Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL™ 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, *5*(1), 2. https://doi.org/10.1186/1477-7525-5-2
27. Rajmil, L., López, A., López-Aguilà, S., & Alonso, J. (2013). Parent–child agreement on health-related quality of life (HRQOL): a longitudinal study. *Health and Quality of Life Outcomes*, *11*(1), 101. https://doi.org/10.1186/1477-7525-11-101
28. Erhart, M., Ellert, U., Kurth, B. M., & Ravens-Sieberer, U. (2009). Measuring adolescents' HRQoL via self reports and parent proxy reports: an evaluation of the psychometric properties of both versions of the KINDL-R instrument. *Health and Quality of Life Outcomes*, *7*(1), 77. https://doi.org/10.1186/1477-7525-7-77
29. Eiser, C., & Varni, J. W. (2013). Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *European Journal of Pediatrics*, *172*(10), 1299–1304. https://doi.org/10.1007/s00431-013-2049-9

Figures

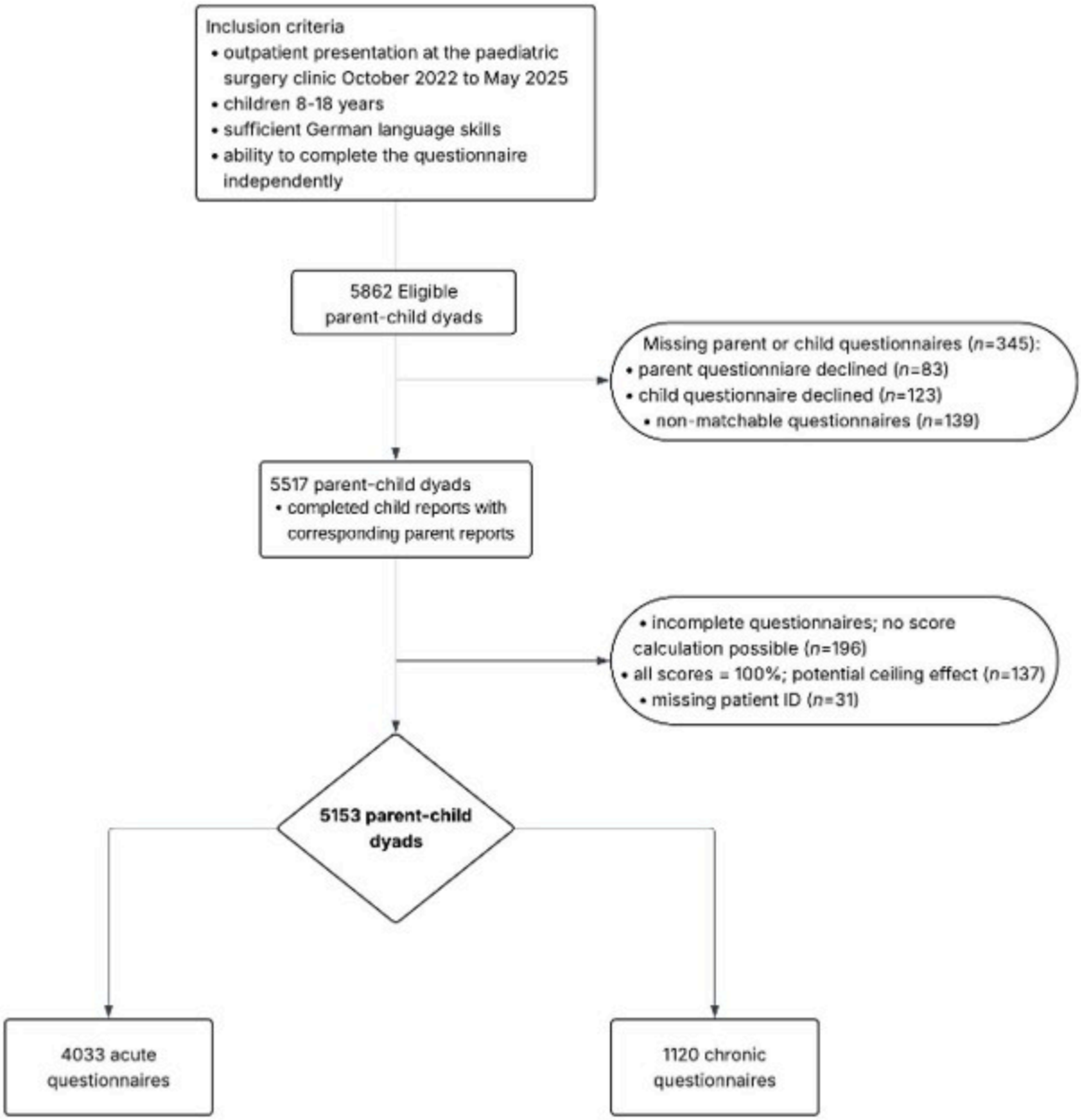


Figure 1

Flowchart of participant inclusion and exclusion

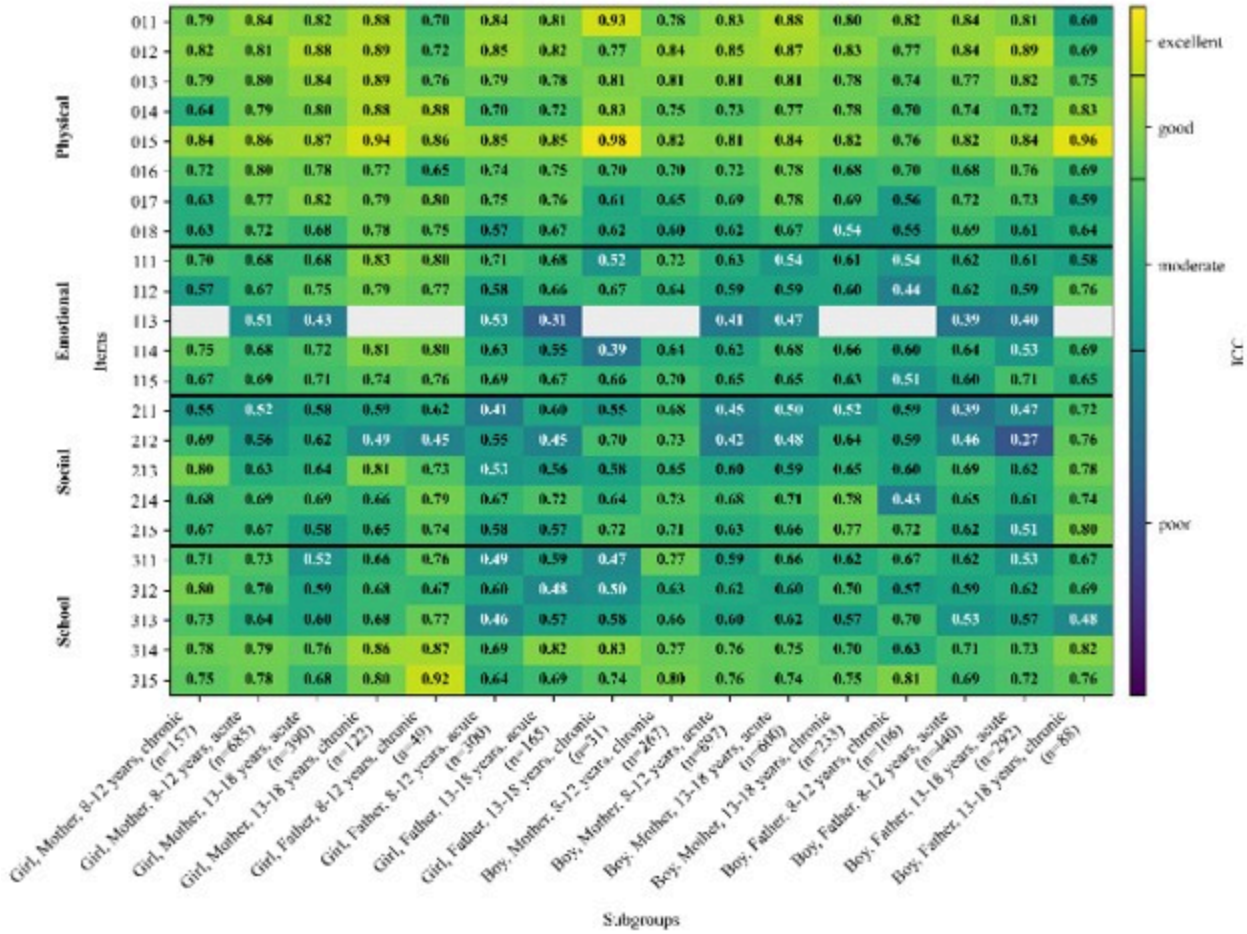


Figure 2

Heatmap of Item-level ICC by Subgroup

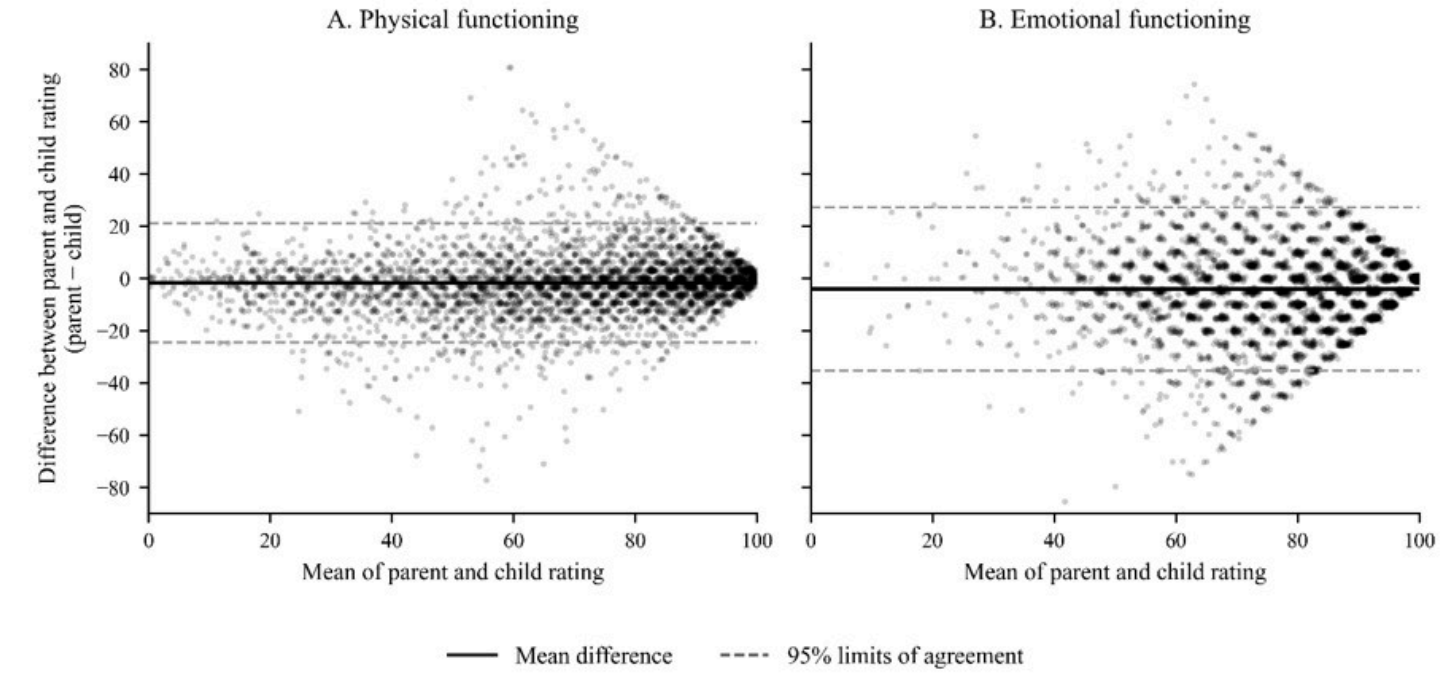


Figure 3

Bland-Altman plots for physical and emotional functioning

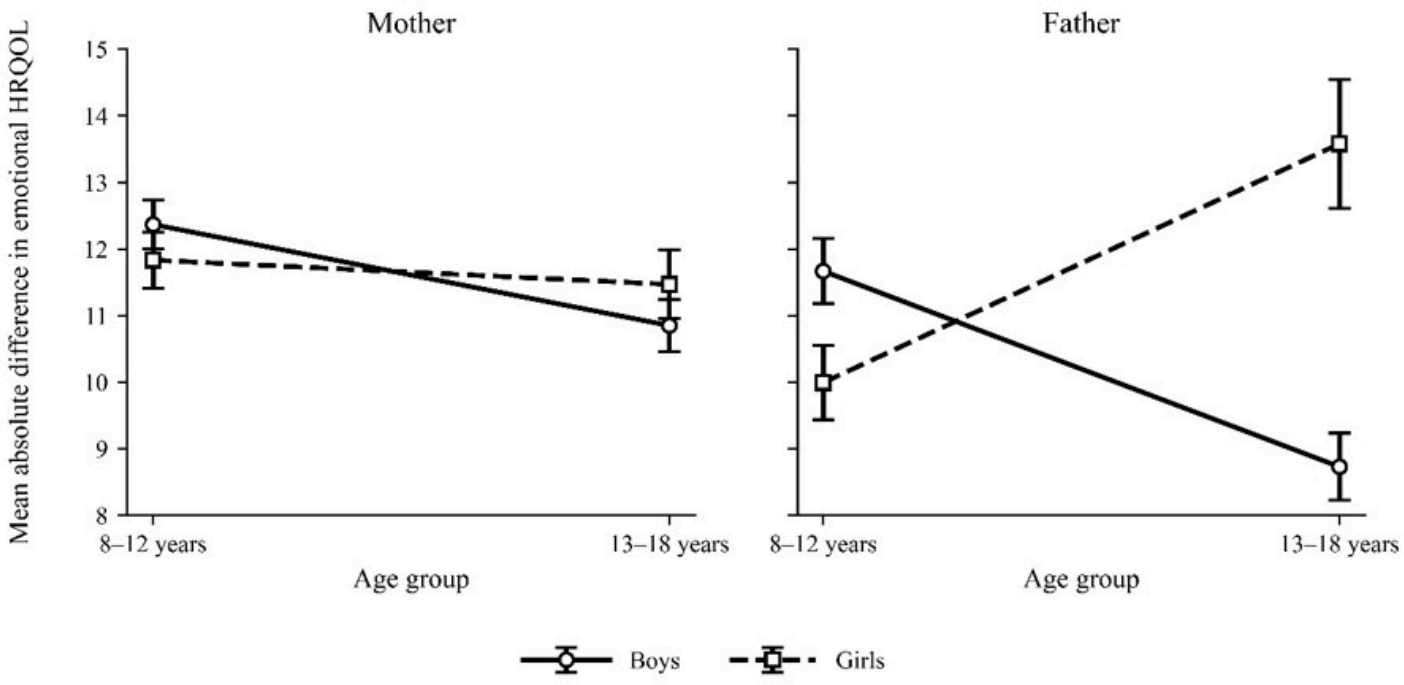


Figure 4

Mean parent-child differences in emotional HRQOL across age groups by reporting parent and child gender