#### **ORIGINAL ARTICLE**



# Youth and parent perceptions of parenting in childhood cancer survivors and healthy peers

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Received: 17 January 2018 / Accepted: 21 May 2018 / Published online: 3 June 2018 © Springer-Verlag GmbH Germany, part of Springer Nature 2018

# Abstract

**Purpose** Having a child diagnosed with cancer may have a long-term impact on parenting practices. The aims of this study were to (a) examine possible differences in youth and parent perceptions of parenting between childhood cancer survivors and healthy comparisons, (b) determine the concordance between youth and parent perceptions of parenting, and (c) explore differences in parent-youth concordance between survivors and healthy comparisons.

**Methods** Participants were youth aged 8–18 years (N = 170 childhood cancer survivors, N = 114 healthy comparisons) and one of their parents. All patients were  $\geq 3$  years from diagnosis (M = 6.52, SD = 3.60). Both youth (Parental Bonding Instrument (PBI)) and parents (Parenting Relationship Questionnaire (PRQ)) reported on their perceptions of parenting. Two separate MANCOVA's (PBI and PRQ) were conducted to determine possible differences between childhood cancer survivors and healthy peers. Concordance between youth and parent perceptions of parenting was examined.

**Results** Survivors did not differ from healthy peers in their perception of parental care and overprotection (p = .890). Likewise, parents in the survivor and healthy peer groups did not differ in their perceptions of involvement, attachment, communication, confidence, or relational frustration (p = .360). Youth's report of a caring parent-child relationship was positively associated with parent-reported involvement, attachment, communication, and parenting confidence and negatively associated with parent-reported relational frustration. Youth-perceived overprotection was positively associated with parent-reported relational frustration. No differences were found in parent-youth concordance between survivors and healthy comparisons.

**Conclusion** A history of childhood cancer does not appear to adversely influence parenting behavior, as perceived by both youth and their parents.

Keywords Parenting · Childhood cancer survivors · Self-report · Parent report · Healthy comparisons

# Abbreviations

SESSocioeconomic statusMANCOVAMultivariate analysis of covariance

# Introduction

Though survival rates have improved greatly in the past decades, childhood cancer still remains a highly stressful event, with potentially devastating effects on youth and their families

Sean Phipps sean.phipps@stjude.org [1, 2]. Although most survivors of childhood cancer and their families seem to adapt well over time, there is a body of research that shows that the psychosocial impact of a cancer diagnosis may vary. For instance, meta-analytic and systematic review findings show that the majority of families in pediatric cancer are resilient in the long term [3, 4], but still 6-15% of childhood cancer survivors [5] and 20-22% of parents experience some form of psychological distress [4]. Numerous studies have found that the parent-child relationship is important to children's long-term adjustment and achievement [6-10]. A history of childhood cancer might make families more prone to perceive their child as vulnerable and employ overprotective parenting practices [11, 12]. Protective behaviors that might have been helpful during treatment may not be beneficial anymore once the child returns to normal life and enters long-term survivorship. Factors that are known to strengthen perceived child vulnerability and parental overprotection are a perception

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of the illness as life-threatening, environmental stress, family stress, a lack of social support, low socioeconomic status, and parental health problems [13].

The current literature is inconclusive about the long-term effect of a pediatric cancer diagnosis on parenting practices. For instance, a less positive parent-child relationship (i.e., less parental warmth, higher parental control, and overprotection) has been reported for children with a chronic physical illness compared to healthy comparisons [14, 15]. In addition, mothers of (newly diagnosed) pediatric cancer patients seem to report more family conflict than healthy comparison samples [16]. Finally, in a study that looked at the behavioral side effects of pediatric acute lymphoblastic leukemia treatment, it was found that parents showed higher lax and bribing parenting strategies, but not more parental overprotection, positive parenting, or inconsistent discipline parenting [17].

While the above-mentioned studies seem to imply a negative influence of a pediatric cancer diagnosis on parenting practices, other studies report no difference [3, 14, 18, 19] or only a small impact [11]. For example, Hullmann et al. [11] found that only 16% of parents of pediatric cancer patients showed significant levels of parental overprotection. Similarly, Tillery et al. [18] did not find any differences between parental care and overprotection in children with cancer and healthy comparisons. Slightly more positive outcomes (e.g., higher levels of parental care) in comparison to healthy population norms [20] or published cut-off scores [21] have also been reported for adolescents with cancer. Indeed, aside from the obvious negative consequences of a pediatric cancer diagnosis, families are often capable of experiencing positive outcomes, such as post-traumatic growth and strengthened family relationships [22-24].

In addition, the current literature regarding parenting of children with cancer has primarily focused on the perspective of the parent, with limited focus on the youth's perspective. However, as parent and child perspectives may differ, it is therefore important to look at both views simultaneously [25–28]. There is a body of research addressing the need for including both parent and youth-reported outcomes, since they seem to only marginally relate to each other [25-28]. In addition, previous studies have often failed to include healthy age-matched comparison groups, such that the actual impact of health status remains unclear. In sum, the current study wants to address two shortcomings in the current body of literature: first taking into account perspectives from both informants, and second, the inclusion of a healthy age-matched comparison group. Therefore, this study aimed to (a) examine youth and parent-reported perceptions of parenting in childhood cancer survivors and healthy peers, (b) determine the associations between parent-youth perceptions of parenting, and (c) explore possible differences in the parent-youth concordance across childhood cancer survivors and healthy peers.

# **Methods**

#### Participants and procedure

The current study was part of a larger longitudinal project measuring coping and adjustment in children with cancer and their parents. Participants for the larger study were assessed at three time points: at baseline (T1), 1 year later, (T2), and 3 years later (T3). Eligibility criteria were (1) child aged between 5 and 15 years at the start of the study, (2) speak English, and (3) not having a significant cognitive or sensory deficit. Cancer patients had to be at least 1 month post-diagnosis at T1 and healthy comparisons should not have had a life-threatening or chronic condition. Cancer patients were stratified by time since their diagnosis at baseline, with patients evenly distributed across four strata (1-6 months, 6 months-2 years, 2-5 years, and 5+ years from diagnosis). Data for the current study were obtained from youth (aged 8–18 years) and their primary caregiver at T3. In the current study, we were focused on parenting measures completed both by youth and their parents, which took place only at T3. Therefore, data from earlier time points were not considered [18, 23]. Childhood cancer survivors had been treated at a large children's hospital in the mid-south of the USA. Healthy peers were collected from schools in a threestate area surrounding the hospital. The institutional review board approved of the study and informed consent was obtained from all participants. At T3, participants received a \$25.00 gift card as compensation.

#### Measures

#### Sociodemographic and medical information

Parents reported on their age, gender, educational and occupational level, and marital status. Youth reported on their age and gender. Family socioeconomic status (SES) was calculated using the Barratt Simplified Measure of Social Status [29]. Scores can range from 8 to 66 and are categorized into 5 groups, ranging from high to low SES: group I (scores 56–66), II (scores 51–55), III (scores 41–50), IV (scores 31–40), and V (scores 8–30). For the current study, groups were recoded into "low SES" (groups IV and V), "medium SES" (group III), and "high SES" (groups I and II). For youth with a history of cancer, diagnoses and treatment information were obtained from the medical record.

#### Parental bonding instrument

This 25-item questionnaire [30] measures the fundamental parenting styles of parental care (12 items) and overprotection (13 items) as perceived by the child. Items are measured on a four-point scale, ranging from 0 "very unlike" to 3 "very

like." The original measure assesses child's perceptions of parenting in a retrospective manner. For the current study, the dimensions of care and overprotection were slightly adjusted to be able to measure children's current perceptions of parenting (e.g., "Seemed emotionally cold to me" into "Seems emotionally cold to me" and "Tended to baby me" into "Tends to baby me"). The parental bonding instrument (PBI) has been shown to have good psychometric properties with long-term stability over time [31]. For the current sample, internal consistency was good for the PBI care ( $\alpha = 0.87$ ) and overprotection ( $\alpha = 0.81$ ) scale.

#### Parenting relationship questionnaire (BASC-3 PRQ)

This 71-item instrument [7] assesses the parent-child relationship on 8 different scales: attachment, communication, discipline practices, involvement, parenting confidence, satisfaction with school, and relational frustration. Parents in the current study only completed the scales on attachment (11 items), communication (9 items), involvement (8 items), parenting confidence (8 items), and relational frustration (14 items). Items were rated on a four-point scale ranging from "Never" to "Almost always." T-scores that correct for youth's age and parent's gender can be calculated with a mean of 50 and a standard deviation of 10. Reliability for the scales in the current sample was good and Cronbach's alpha ranged from 0.80 to 0.88.

# **Statistical analysis**

Independent *t*-tests and chi-square tests were conducted to compare background characteristics between childhood cancer survivors and healthy peers (i.e., child age, child gender, child race, parent age, parent gender, parent socioeconomic status (SES), and parent marital status). Two separate (child PBI and parent PRQ) multivariate analyses of covariance (MANCOVAs) were performed to examine if perceptions of parenting differed between childhood cancer survivors and healthy comparisons and to test whether their parents differed in their perceptions of parenting. In the youth PBI MANCOVA, we controlled for child age, gender, parent gender, family SES, and parent marital status. Since the T-scores from the PRQ were already corrected for child age and parent gender, we only corrected for child gender, family SES, and parent marital status in the parent MANCOVA. To determine the concordance between parent and youth perceptions of parenting, Pearson correlation coefficients (r) between the PBI and the PRQ scales were calculated separately for childhood cancer survivors and healthy comparisons. To assess the significance of the difference between the r of childhood cancer survivors and the r of healthy comparisons, the Fisher *r*-to-z transformation was used.

# Results

# **Participants**

A total of 431 (N = 227 youth with cancer; N = 204healthy peers) youth (aged 5-15 years) and their parents were enrolled at the start of the study. Of the initial participants that were enrolled at baseline, 170 childhood cancer survivors and one of their parents (75%) completed parenting measures for the current study assessment (third time point). In the healthy comparison group, 114 participants (56%) completed parenting measures for the current study. Participants that completed both the baseline and T3 assessment did not differ on background characteristics with participants that only completed the baseline measures. Background characteristics of the sample are listed in Table 1. At the third time point, childhood cancer survivors and healthy comparisons did not differ with regard to child gender, race, parental age, or parental gender. However, childhood cancer survivors were a bit older on average and less often had parents that were married.

# Parenting practices in childhood cancer survivors and healthy peers

Results from the two separate MANCOVAs revealed no significant differences between childhood cancer survivors and healthy peers in either the way youth ( $\Lambda = 0.999$ , F(2, 266) = 0.12, p = .890,  $\eta^2 = 0.001$ ) or their parents ( $\Lambda = 0.980$ , F(5, 271) = 1.10, p = .360,  $\eta^2 = 0.02$ ) perceived parenting. Descriptively, the means across all youth-reported PBI and parent-reported PRQ subscales were similar in both the childhood cancer survivor and the healthy comparison group (see Table 2 for descriptive statistics).

Child age, parent gender, SES, and marital status were not significant predictors of either youth or parent-reported perceptions of parenting. Child gender was a significant predictor of parent-reported perceptions of parenting (A =0.988, F(5, 271) = 3.88, p < .01,  $\eta^2 = 0.07$ ). Separate univariate ANOVAs on the PRQ revealed that parents perceived less relational frustration (F(1, 275) = 11.51, p< .01,  $\eta^2 = 0.04$ ) and more parenting confidence (F(1,275) = 8.02, p < .01,  $\eta^2 = 0.03$ ) with boys than with girls. No gender differences were found regarding parental involvement (p = .846), attachment (p = .769), and communication (p = .811).

# Concordance between youth and parent perceptions of parenting

As is shown in Table 2, for both childhood cancer survivors, as well as for healthy peers, there were statistically significant, although small to medium positive correlations, between Table 1Backgroundcharacteristics of childhoodcancer survivors and healthypeers. M = Mean, SD = StandardDeviation

	Survivors ( $N = 170$ )		Healthy peers ( $N = 114$ )		р
	N	%	N	%	
Child age (years), $M \pm SD$ 013	14.04	2.59	13.22	2.75	
8–12 years	49	28.8	44	38.6	
13–18 vears	121	71.2	70	61.4	
Child gender					
921					
Male	89	52.4	59	51.8	
Female	81	47.6	55	48.2	
Child race					
622					
Black	37	21.8	23	20.2	
White	127	74.7	87	76.3	
Other	6	2.3	4	3.5	
Child diagnosis					
Acute lymphoblastic leukemia	46	27.1	_	_	
$Other leukemia^a$	11	6.5	_	_	
Hodgkin's and non-Hodgkin's lymphoma	21	12.4	_	_	
Solid tumor	63	37.1	_	_	
Brain tumor	29	17.1	_	_	
Child time since diagnosis (years), $M \pm SD$	6.52	3.60	_	_	
Child time off therapy (years), $M \pm SD$	5.27	3.74	_	_	
Child relaysed					
No	141	82.9	_	_	
Yes	29	17.1	_	_	
Parent age (years), $M \pm SD$	42.80	6.61	43.92	11.34	
292					
Parent gender					
276					
Mother	148	87.1	104	91.2	
Father	22	12.9	10	8.8	
Parent socioeconomic status					
026					
Low (groups IV and V)	64	37.6	26	22.8	
Medium (group III)	54	31.8	41	36.0	
High (groups I and II)	52	30.6	47	41.2	
Parent marital status					
001					
Married	110	64.7	94	82.5	
Single	21	12.4	6	5.3	
Divorced	29	17.1	13	11.4	
Separated	10	5.9	1	0.4	
•					

M mean, SD standard deviation

<sup>a</sup> Other leukemia category includes acute myeloid leukemia, acute biphenotypic leukemia, and acute promyelocytic leukemia

youth-reported parental care and parent-reported attachment, communication, and parenting confidence. In addition, there was a significant moderate inverse correlation between youthreported parental care and parent-reported relational frustration. Thus, youth who reported on a more positive parentchild relationship also had parents that reported more positively on the relationship with their child. Furthermore, a significant small to medium positive correlation was found between youth-reported parental overprotection and parent-reported relational frustration across both groups.

# Differences in concordance across childhood cancer survivors and healthy peers

In the healthy comparison group, there was a significant small to medium positive correlation between youthreported care and parent-reported involvement, a correlation not found for childhood cancer survivors. Finally, no significant differences were found in the magnitude of the parent-youth correlations in the cancer survivor group compared to the healthy comparison group. Thus, childhood

Table 2	Correlations	among parent-	-youth pe	rceptions of	parenting i	in survivors a	nd healthy peers
			~ .				~ .

	1. PBI care	2. PBI overprotection	3. PRQ Involvement	4. PRQ Attachment	5. PRQ Communication	6. PRQ Parenting confidence	7. PRQ Relational frustration
1. PBI care	_	45***	.19*	.33**	.28**	.37***	29**
2. PBI overprotection	40***	_	16	14	03	16	.29**
3. PRQ Involvement	.12	03	-	.58***	.59***	.46***	37***
4. PRQ Attachment	.20*	05	.56***	_	.62***	.64***	37***
5. PRQ Communication	.19*	03	.58***	.66***	_	.50***	24*
6. PRQ Parenting confidence	.20*	01	.45***	.67***	.56***	_	59***
7. PRQ Relational frustration	31***	.20**	21**	40***	43***	57***	-
Childhood cancer survivors [ <i>M</i> ( <i>SD</i> )]	29.09 (5.91)	14.45 (7.04)	50.31 (11.12)	49.84 (8.77)	49.90 (9.36)	47.40 (9.49)	48.57 (9.23)
Healthy comparisons [ <i>M</i> ( <i>SD</i> )]	28.80 (6.10)	15.47 (7.20)	47.05 (9.43)	47.07 (8.37)	46.98 (10.18)	44.24 (9.68)	51.18 (8.86)

Correlations above the diagonal represent associations within the healthy comparison group (N=114) and correlations below the diagonal show associations within the childhood cancer survivor group (N=170)

*PBI* parental bonding instrument (youth report), *PRQ* parenting relationship questionnaire (parent report), *M* mean, *SD* standard deviation \*p < .05; \*\*p < .01; \*\*p < .01

cancer survivors showed similar congruence in parentyouth perceptions of parenting as healthy peers.

# Discussion

Despite the potential trauma and accompanying late effects of a history of a childhood cancer diagnosis [32–35], the current study revealed no differences in parenting behavior between childhood cancer survivors and healthy peers by both youth and parent-report. In addition, no differences were found between groups in the congruence between parent and child reports of perceived parenting. These findings strengthen the literature in supporting that even though a history of childhood cancer can be stressful for families, it does not have a significant adverse impact on long-term parenting practices. This is in line with literature that reports on similar parenting outcomes for youth with a history of cancer when compared to healthy norms or healthy comparison samples [14, 18–21]. In other words, this suggests that parents of children with cancer should not be perceived as being at any higher risk for overprotective behaviors, or other less healthy parenting practices.

Relating to congruence of parent-youth perceptions, we found small to moderate positive associations between youth-reported positive parenting perceptions (i.e., higher parental care) and parent-reported positive parenting practices (i.e., more attachment, communication, and parenting confidence and less relational frustration). There was also a significant low-to-moderate positive association between youth's perceptions of overprotection and parent-reported relational frustration that was observed across both groups. These findings are in concordance with the general literature on parent-child congruence. For example, in their meta-analysis on parent-child agreement of emotional and behavioral problems, Achenbach et al. [28] found that the average association between child and parent-report was moderate (r = .25). Similarly, the meta-analytic findings of Korelitz and Garber [27] report low to moderate agreement in parent-child congruence of parenting behaviors (r = .23-.29). Our findings underscore that since parent and child report were only marginally correlated, it is optimal to include both youth and parent report when studying parenting practices in childhood cancer survivors.

Clinically, this study is informative in identifying how survivors' report of their parenting perceptions relates to parent-report of their parenting. That is, youth who perceived their parents as more overprotective had parents that reported on more relational frustration with their child. This finding might warrant future interventions for children with cancer and their families. In addition, the fact that we found that parents in our study sample tended to experience more relational frustration and less parenting confidence with girls, might be a direct consequence of the large percentage of mothers as compared to fathers that was participating in our study. In the adolescent literature, it has also been reported that most parent-child disagreements involve mothers [36]. Likewise, gender has found to be associated with the degree of parent-child congruence [27]. Unfortunately, the relatively small number of fathers that were involved in our study did not allow us to look at a child gender by parent gender interaction effect on relational frustration. Future studies should take a possible gender effect into account and could look at factors that might relate to parenting practices, such as the role of parental distress on parenting practices and youth adjustment outcomes.

Some study limitations should be considered. First, although we attempted to obtain a demographically matched comparison group, there were significant differences in child age and parental SES and marital status between childhood cancer survivors and healthy comparisons. However, this was mitigated by correcting for these variables in our MANCOVA, and neither were significant covariates. Second, since we were interested to compare parent and child report, we selected an age range of 8-18 years. Subsequent studies could address parenting in younger age groups to see if similarity in parenting practices remains for parents of healthy children and parents of childhood cancer survivors. For instance, more lax parenting strategies have been found for children aged 2-6 years in the maintenance phase for acute lymphoblastic leukemia compared to healthy children [17]. In addition, to reduce burden for children and their families, we only included scales that we were most interested in. We did not include the PRQ subscales of discipline practices and satisfaction with school. Future studies could examine if parenting in childhood cancer survivors is affected by these domains. Third, as previously mentioned, our sample was collected from a single institution and we had only a small number of fathers participating. In a sample with a larger number of fathers, it would be interesting to compare whether different interactions and congruence in parenting perceptions occur in same versus different sex parent-child dyads. In this regard, it should be noted that parenting from the perspective of one child and one parent covers a narrower construct than the family environment as a whole. It may be that the co-parent has a buffering (or harmful) influence on child outcomes [37]. Future research should attempt to obtain perspectives of and by both parents and take the other parents' perspective into account when examining predictors and outcomes of a healthy family environment.

To conclude, a history of a life-threatening illness such as childhood cancer does not appear to adversely influence long-term parenting behavior, as perceived by both youth and their parents. However, children who experienced their parents to be overprotective had more frustrations in the parent-child relationship. This warrants further research on the impact of parent-child relationships on the adjustment outcomes of childhood cancer survivors. **Funding information** This study was funded, in part, by a grant from the National Institutes of Health (R01 CA136782) and by the American Lebanese-Syrian Associated Charities (ALSAC).

# **Compliance with ethical standards**

The institutional review board approved of the study and informed consent was obtained from all participants.

**Conflict of interest** The authors declare that they have no conflicts of interest.

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