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Mona L. Peikert[1] | Laura Inhestern[1] | Konstantin A. Krauth[2] |
Gabriele Escherich[3] | Stefan Rutkowski[3] | Daniela Kandels[4] | Corinna Bergelt[1]

[1]Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

[2]Department of Pediatrics, Pediatric Hematology & Oncology, Klinik Bad Oexen, Bad Oeynhausen, Germany

[3]Clinic of Pediatric Hematology and Oncology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

[4]Swabian Children's Cancer Center, Medical Faculty, University of Augsburg, Augsburg, Germany

Correspondence
Mona L. Peikert, University Medical Center Hamburg-Eppendorf, Department of Medical Psychology, Martinistraße 52, Hamburg 20246, Germany.
Email: m.peikert@uke.de

Abstract

Objective: Fear of progression (FoP), also referred to as fear of cancer recurrence, is gaining increasing interest in survivorship research as it constitutes a great burden for patients and relatives. However, only little is known about FoP in parents of childhood cancer survivors. The objective of this study was to investigate the impact of FoP on quality of life (QoL) in parental couples.

Methods: We analyzed dyadic data of 197 couples parenting childhood cancer survivors (aged 0-17 years at diagnosis of leukemia or central nervous system tumor) after the end of intensive cancer treatment. The actor-partner interdependence model calculated by structural equation modelling was used to examine actor effects (effect of one's own FoP on one's own QoL) and partner effects (effect of one's own FoP on the partner's QoL).

Results: Eighty-one percentage of the parents reported moderate or high FoP levels. Mothers reported higher FoP levels ($p < .01$) and lower overall QoL levels than fathers ($p < .01$). The results revealed a significantly positive intra-dyadic correlation between FoP of mothers and fathers of the same dyad ($r = .431$, $p < .001$). We found significantly negative actor effects for both mothers and fathers for the overall QoL ($p < .001$) as well as for several QoL subscales. No significant partner effects were found.

Conclusions: Most parents reported elevated levels of FoP. Our results show that FoP in parents of childhood cancer survivors is strongly negatively associated with QoL. Parental FoP should therefore be explored in future research and needs to be targeted by health care providers.

KEYWORDS
cancer, central nervous system tumors, fear, leukemia, oncology, parents, pediatrics, psycho-oncology, quality of life, survivors

1 | INTRODUCTION

Childhood cancer is the second leading cause of death in children in high income countries.[1] Each year, more than 2000 children in Germany under 18 years of age are diagnosed with cancer.[2] The 15-year survival rate is approximately 80%.[2] Consequently, the population of childhood cancer survivors and their families is growing.[1] Most families successfully readjust after the end of treatment and show distress levels comparable to normative samples.[3,4] However, some parents still report clinical levels of distress years after the end of treatment.[3-5]

Fear of progression (FoP), also known as fear of cancer recurrence or fear of relapse, is gaining an increasing interest in adult survivorship research.[6] FoP describes a rationally explainable response to the real threat of a potentially life-threatening cancer disease.[7] It can be defined as the "fear that the illness will progress with all its biopsychosocial consequences, or that it will recur."[7] FoP in adult cancer patients has been researched intensively.[6] For a long time, FoP in parents of childhood cancer survivors was only implicitly described in qualitative studies.[4,8-11] The Fear of Progression Questionnaire for the parental perspective (FoP-Q-SF/PR) was published recently and offers the opportunity to investigate parental FoP systematically.[12,13] Parental FoP seems to be associated with anxiety, depression, posttraumatic stress and a low quality of life (QoL).[13] Further, significantly negative correlations of FoP with time since diagnosis, anxiety coping skills of the parents, parental age, the child's current medical condition and the number of siblings were found.[12] Significant gender differences in FoP levels of mothers and fathers could not be found,[12,14] nor was the child's age at diagnosis associated with parental FoP.[12] According to an expert online survey in Germany, health care professionals are frequently confronted with parental FoP in clinical practice.[15] Additionally, a recent interview study identified parental FoP as an impeding factor when reintegrating into daily life after the end of treatment.[16]

Overall, research on FoP of parents of childhood cancer survivors is still in its infancy. Previous studies used a broad sample of parents from children still receiving cancer treatment to long-term survivors.[12-14] Further, most of the parents that participated in these studies already received psychosocial support.[12-14] A family perspective has not been considered yet, however, according to research on FoP in adult patients, FoP seems to be a "family affair."[7] The aim of this study was to investigate how FoP impacts the QoL of affected parents using a dyadic data analysis approach. We decided for QoL as the outcome, since it is commonly used for the assessment of the multidimensional psychosocial situation of pediatric cancer patients and their families.[17-19] We additionally examined the association between FoP and various QoL subscales (functioning, satisfaction with the family situation, emotional distress, self-development, general well-being) to elaborate on different aspects of QoL.

Based on earlier results we examined the following hypotheses[12,13]:

1. Actor effect: FoP in mothers/fathers of childhood cancer survivors is negatively associated with their own QoL (overall QoL and QoL subscales).
2. Partner effect: FoP in mothers/fathers of childhood cancer survivors is negatively associated with their partners' QoL (overall QoL and QoL subscales).

2 | METHODS

2.1 | Design

This dyadic data analysis was performed within a prospective observational study with a longitudinal mixed-methods design. The overall study has been described in a study protocol[20] and was reviewed and approved by the Ethics Committee of the Medical Chamber of Hamburg (number: PV5277). The STROBE Statement was applied in the reporting of this article.[21]

2.2 | Participants and procedure

In this study, we focused on the most frequent pediatric cancer diagnoses in Germany, leukemia and central nervous system (CNS) tumors.[2] We included biological parents and other caregivers of children (<18 years of age at diagnosis) after the end of intensive cancer treatment (eg, chemotherapy). Exclusion criteria were assessed by the health care providers in the clinics and were refusal of participation, physical and/or mental burden (applicable if the study participation would be overly burdensome), cognitive limitations and insufficient German language skills. Written informed consent was obtained. The dyadic analysis was performed with data of opposite-sex couples that both participated in the study and that were still in a couple relationship. Same-sex couples were excluded from the analysis because the statistical model requires distinguishable couples (in our study distinguishable by gender).[22]

Parental couples were consecutively recruited in Germany from July 2016 to March 2019 via two study arms: Firstly, we recruited families via the International HIT-MED Registry (I-HIT-MED; ClinicalTrials.gov Identifier: NCT02417324), the study registries of the COALL 08-09 study (ClinicalTrials.gov Identifier: NCT01228331) and the SIOP-LGG 2004 study (ClinicalTrials.gov Identifier: NCT00276640). The study registries informed the patients' clinic after the end of intensive cancer treatment about the study. Health care providers at the clinics informed the families about the study and passed study information and a consent form to contact the family. The research institute finally sent the families consent forms for participation and the questionnaires. Secondly, our cooperating rehabilitation clinic informed families about the study and passed study information, consent forms for participation and questionnaires to the families. Parents were surveyed at the beginning of the rehabilitation measure. A flowchart of the recruitment process can be found in Appendix A.

2.3 | Measures

2.3.1 | Sociodemographic and medical data

Sociodemographic information was extracted from the parents' questionnaire (age and gender of parents and child, number of siblings, parent's education and employment status, relationship status of the parental couple). Depending on the recruitment path, medical information (diagnosis, time since diagnosis) was extracted from the parents' reports or the physicians' questionnaire in the rehabilitation clinic.[20]

2.3.2 | Fear of progression

In this study, we used the 12-item Fear of Progression Questionnaire - Parent Report (FoP-Q-SF/PR).[12] Items are scored on a 5-point Likert

scale ranging from never (1) to very often (5). A sum score between 12 and 60 can be calculated with higher scores indicating a higher level of fear of progression. Schepper and colleagues recommended preliminary cut-off values based on the mean value ±1 *SD*: 12 to 25 low FoP, 26 to 46 moderate FoP and 47 to 60 high FoP.[12] The FoP-Q-SF/PR shows good reliability and validity.[12,13]

2.3.3 | Quality of life

Parental QoL was measured with The Ulm Quality of Life Inventory for Parents (ULQIE).[23] The ULQIE measures QoL in parents of chronically ill children with 29 items on five subscales focusing on the past week: Functioning, satisfaction with family situation, emotional distress, self-development and general well-being.[23] Items are scored on a 5-point Likert scale from never (0) to always (4). A total sum score and subscale scores can be calculated. High sum scores indicate high QoL. The ULQIE has adequate psychometric properties.[23]

2.4 | Statistical analyses

Sociodemographic and medical characteristics, group comparisons (unpaired *t*-tests, Pearson chi square test) and intra-dyadic correlations (Pearson correlations) were analyzed with the software *IBM SPSS Statistics 25*. Alpha was for all analyses set at .05. Missing values in the FoP and QoL measures were imputed with the individual mean with a maximum of 30% missing data within one scale. The sample size and power calculations were based on the main research questions in the overall study. Based on previous statistics and an estimated 50% response rate, we expected a total number of 285 families at the first measurement time point in the two study arms. An extension of the recruitment phase was necessary. A comprehensive description is displayed in the study protocol.[20]

2.4.1 | Actor-partner interdependence model (APIM)

When analyzing parental couple data, it is important to note that the dyad members' responses might be dependent.[24] This would lead to a violation of the independence assumption in significance testing. The actor-partner interdependence model (APIM) directly measures non-independence by considering the dyad in the analysis.[22,24] The APIM examines actor effects (effect of one's own predictor on one's own outcome) and partner effects (effect on one's own predictor on the partner's outcome).[22] We applied the APIM to calculate the effect of one's own FoP on one's own QoL (actor effect) and the effect of one's own FoP on the partner's QoL (partner effect).[22] We conducted the APIM using structural equation modeling (SEM) with maximum likelihood estimation.[25] The SEM was calculated with the program lavaan[26] within the app APIM_SEM.[27] The parameter k is the ratio of the partner effect to the actor effect and was calculated to detect

patterns in the APIM (couple pattern, contrast pattern, actor-only pattern).[28] The child's diagnosis (CNS tumor vs leukemia), time since diagnosis and the child's age were examined as potential confounders. Controlling for confounders is recommended if variables correlate with both the predictor (FoP) and the outcome (QoL) or with the outcome only.[27]

3 | RESULTS

3.1 | Sample characteristics

Eight hundred ninety-nine families were potentially eligible for participation in the study (Appendix A). Three hundred twelve families participated in the survey. Due to the complex recruitment process, we could only indicate the reasons for the non-participation of the 60 families that were recruited at the rehabilitation clinic (*n* = 21 refusal of participation, *n* = 14 insufficient German language skills, *n* = 12 physical and/or mental burden, *n* = 3 cognitive limitations, *n* = 10 not specified). Five hundred twenty-seven families that were recruited via the study registries did not participate because either they did fulfil the exclusion criteria (refusal of participation, physical and/or mental burden, cognitive limitations or insufficient German language skills) or the health care providers in the clinics were not able to inform them about the study. From the 312 families that participated in the study, five families were excluded subsequently (*n* = 2 missing consent forms for participation, *n* = 2 wrong diagnosis, *n* = 1 incorrectly answered questionnaires because of limited German language skills). In this study, we analyzed the dyadic data of 197 parental couples (107 families recruited at the rehabilitation clinic and 90 via the study registries). Table 1 provides an overview of the relevant sociodemographic and medical data of parents and patients. There were no significant differences in time since diagnosis (*t*[366.530] = 1.801, *p* = .072) and FoP levels (*t*[389] = −0.811, *p* = .418) between parents in the two recruitment paths. However, we found that parents recruited at the rehabilitation clinic reported significantly lower QoL levels than parents recruited via the study registries (*t*[388] = −2.088, *p* < .05).

3.2 | FoP and QoL in mothers and fathers

Descriptive data on parent's FoP and QoL as well as gender differences are presented in Table 2.

3.3 | Confounders

We found significantly positive correlations between FoP and diagnosis (*r* = .206, *p* < .001), time since diagnosis (*r* = .194, *p* < .001) and child's age (*r* = .108, *p* < .05). FoP in parents of CNS tumor survivors was significantly higher than in parents of leukemia survivors (*t* [389] = −4.160, *p* < .001). Longer time since diagnosis and higher child's age were associated with higher levels of FoP. However, there was

TABLE 1 Sociodemographic and medical data of 394 parents and 197 pediatric cancer patients

Sociodemographic data Parents	Total (n = 394)		Fathers (n = 197)		Mothers (n = 197)	
	M	SD/range	M	SD/range	M	SD/range
Age in years[a]	39.4	7.1/22-70	40.9	7.6/23-70	38.0	6.3/22-60
	n	%	n	%	n	%
Education[b]						
> 10 years	198	52.5	100	53.8	98	51.3
≤ 10 years	179	47.5	86	46.2	93	48.7
Employment status[c]						
Gainfully employed	298	76.6	181	92.8	117	60.3
Full-time	182	61.1	164	90.6	18	15.4
Part-time	116	38.9	17	9.4	99	84.6
Not gainfully employed	62	15.9	10	5.1	52	26.8
Home makers	43	69.4	1	10.0	42	80.8
Seeking employment	14	22.6	6	60.0	8	15.4
Retired	5	8.1	3	30.0	2	3.8
Other	29	7.5	4	2.1	25	12.9

Patients	Total (n = 197)		Boys (n = 109)		Girls (n = 88)	
	M	SD/range	M	SD/range	M	SD/range
Age in years	6.9	4.3/1–18	7.6	4.5/1–18	6.1	4.0/1-16
Time since diagnosis in months	19.0	17.8/5-129	19.2	18.0/6-129	18.9	17.6/5-121
	n	%	n	%	n	%
Number of siblings[d]						
0	33	17.1	15	13.9	18	21.2
1–2	147	76.2	84	77.8	63	74.1
> 2	13	6.7	9	8.3	4	4.7
Cancer diagnosis						
CNS tumor	102	51.8	62	56.9	40	45.5
Leukemia	95	48.2	47	43.1	48	54.5

[a]2 missings.
[b]17 missings.
[c]5 missings.
[d]4 missings.

no significant difference in the QoL levels of parents of CNS tumor and leukemia survivors and no significant correlations with QoL. Therefore, we did not control for any confounders in this dyadic analysis.

3.4 | Main findings

Our results revealed a significantly negative actor effect from FoP on the overall QoL for mothers and fathers (Table 3, Figure 1). We also found significantly negative actor effects for both parents for the QoL subscales functioning, emotional distress and general well-being. A significantly negative actor effect for the subscale satisfaction with the family situation was only found for fathers. The results revealed no significant actor effects for the subscale self-development.

No significant partner effects were found for any of the QoL scales. However, the intra-dyadic correlation of mothers and fathers of the same dyad was significantly positive for both FoP (r = .431, p < .001) and the overall QoL (r = .277, p < .001). An actor-only model (k = 0) for the effect from FoP on the overall QoL was plausible for mothers and fathers since 0 was included in both confidence intervals.[28]

4 | DISCUSSION

The aim of this study was to investigate the impact of FoP on QoL in parents of childhood cancer survivors using a dyadic data analysis approach. Moderate to high levels of FoP were found in 81% of the parents after the end of intensive cancer treatment. FoP levels in our

TABLE 2 Descriptive data on parents' FoP and QoL

	Total (*n* = 394)		Fathers (*n* = 197)		Mothers (*n* = 197)			
	M	**SD/range**	**M**	**SD/range**	**M**	**SD/range**	**t**	**p**
QoL[a23]								
Overall QoL	67.6	17.3/26-109	70.2	17.3/27-109	65.0	17.0/26-105	−3.003	.003
Functioning	16.1	5.2/2-28	16.9	5.3/2–28	15.4	5.0/5-27	−2.862	.004
Satisfaction with family situation	17.7	4.3/4-24	18.0	4.1/5-24	17.4	4.4/4–24	−1.312	.190
Emotional distress	8.7	3.4/0-16	9.1	3.5/0–16	8.2	3.3/1-15	−2.666	.008
Self-development	5.8	3.0/0-14	6.1	2.9/0–14	5.5	3.0/0–14	−1.815	.070
General Well-Being	9.5	3.0/2-16	9.9	3.1/2–16	9.1	2.9/3-16	−2.638	.009
FoP[b12]	33.2	9.3/13-60	32.0	9.7/14-58	34.4	8.7/13–60	2.666	.008
FoP cut-offs[b12]	**n**	**%**	**n**	**%**	**n**	**%**	**χ²**	**p**
Low	76	19.4	50	25.8	26	13.2	9.999	.007
Moderate	280	71.6	127	65.5	153	77.7		
High	35	9.0	17	8.8	18	9.1		

[a]3 to 5 missings.
[b]3 missings.

sample were only slightly lower than in a sample of parents of children up to 10 years after diagnosis of childhood cancer.[13] The mean QoL sum score in our sample was higher than the QoL score in a population of parents of childhood cancer patients in the first 2 weeks post diagnosis, but lower than the QoL score of healthy controls.[29] In contrast to earlier studies, we found a significant gender difference between mothers and fathers with mothers reporting higher levels of FoP.[12,14] Additionally, mothers reported a lower QoL than fathers. It is possible that mothers reported higher burden because they might be the primary carer of the child. Only a few mothers but most of the fathers were working full time. Besides, men reporting lower levels of psychosocial burden is a common finding.[30] As expected, our results display that FoP in mothers and fathers affected the overall QoL (actor effects). We also found a negative impact of FoP on parental functioning, emotional distress and general well-being. FoP also affects the father's satisfaction with the family situation. Self-development of parents was not affected by their FoP.

The results of our study also support the assumption that FoP is a "family affair."[7] FoP in mothers and fathers of the same family were highly correlated. We found a higher intra-dyadic correlation for FoP than for QoL. It is possible that FoP levels are more similar in couples because FoP describes the worry about the couple's child. Further, FoP might be highly influenced by family factors (eg, time since diagnosis) whereas QoL is a multidimensional outcome that might also be affected by various factors outside the family system (eg, job satisfaction). However, there was no association between the FoP of one parent and the QoL of the other parent. One possible reason for this result is the high intra-dyadic correlation between FoP of mothers and fathers from the same family. The partner effect may be confounded by the shared dyadic variance.[31]

FoP was higher in parents of CNS tumor survivors in comparison to parents of leukemia survivors. A correlation of FoP with the actual risk of progression which is higher in CNS tumor survivors is possible.[2] FoP might be associated with a higher age of the child because parents of older children potentially perceive their child's limitations as more severe. A longer time since diagnosis was also associated with higher FoP levels in parents. From a clinical perspective, this might be caused by extending intervals between aftercare appointments. However, since 82% of the families were surveyed in the first 2 years after diagnosis, we cannot make a reliable statement on the course of FoP.

4.1 | Study limitations

For reasons of data protection, we could not contact the parents directly. Thus, we recruited the parents via a rehabilitation clinic and study registries. Our complex recruitment process did not allow for a systematic non-responder analysis. Therefore, the generalizability of the results might be limited. Furthermore, we excluded parents with particularly high levels of physical or mental burden due to ethical considerations. Hence, an underreporting of FoP in our study is possible.

This study has also several strengths. We surveyed parents of childhood cancer survivors throughout Germany and reached a large sample size. Moreover, this is the first study that investigated the association of FoP and QoL in parents of childhood cancer survivors in consideration of intra-dyadic processes.[22,24]

4.2 | Clinical implications

The results of this study display that most parents show moderate to high levels of FoP even after intensive treatment has ended. Additionally, this study provides evidence on the negative impact of parental

TABLE 3 Results of the actor-partner interdependence model (APIM)

	Effect	Estimate	95% confidence interval	p	Beta(s)[a]	r[b]
Overall QoL						
Mothers	Intercept	91.162	[81.480, 100.844]	<.001		
	Actor	−0.799	[−1.078, −0.520]	<.001	−0.409	−0.377
	Partner[c]	0.042	[−0.208, 0.292]	.741	0.024	0.027
	k	−0.053	[−0.358, 0.252]			
Fathers	Intercept	96.340	[86.803, 105.877]	<.001		
	Actor	−0.874	[−1.118, −0.630]	<.001	−0.490	−0.451
	Partner[d]	0.052	[−0.222, 0.325]	.711	0.026	0.032
	k	−0.059	[−0.365, 0.247]			
Functioning						
Mothers	Intercept	21.708	[18.752, 24.665]	<.001		
	Actor	−0.206	[−0.291, −0.121]	<.001	−0.354	−0.324
	Partner[c]	0.023	[−0.053, 0.100]	.546	0.045	0.049
	k	−0.114	[−0.466, 0.238]			
Fathers	Intercept	22.917	[19.812, 26.021]	<.001		
	Actor	−0.220	[−0.299, −0.140]	<.001	−0.399	−0.364
	Partner[d]	0.029	[−0.060, 0.118]	.527	0.047	0.048
	k	−0.131	[−0.518, 0.256]			
Satisfaction with family situation						
Mothers	Intercept	19.800	[17.099, 22.501]	<.001		
	Actor	−0.055	[−0.133, 0.023]	.168	−0.108	−0.100
	Partner[c]	−0.016	[−0.086, 0.054]	.651	−0.036	−0.029
	k	0.293	[−1.207, 1.793]			
Fathers	Intercept	20.946	[18.437, 23.455]	<.001		
	Actor	−0.113	[−0.177, −0.049]	<.001	−0.267	−0.238
	Partner[d]	0.018	[−0.054, 0.090]	.623	0.038	0.038
	k	−0.159	[−0.761, 0.443]			
Emotional distress						
Mothers	Intercept	15.572	[13.867, 17.276]	<.001		
	Actor	−0.218	[−0.267, −0.169]	<.001	−0.570	−0.531
	Partner[c]	0.004	[−0.040, 0.048]	.849	0.013	0.020
	k	−0.020	[−0.219, 0.180]			
Fathers	Intercept	15.583	[13.785, 17.381]	<.001		
	Actor	−0.207	[−0.253, −0.161]	<.001	−0.577	−0.536
	Partner[d]	0.005	[−0.046, 0.057]	.846	0.013	0.018
	k	−0.025	[−0.271, 0.222]			
Self-development						
Mothers	Intercept	8.200	[6.396, 10.004]	<.001		
	Actor	−0.043	[−0.095, 0.009]	.108	−0.125	−0.118
	Partner[c]	−0.037	[−0.084, 0.009]	.116	−0.122	−0.114
	k	0.873	[−0.949, 2.695]			
Fathers	Intercept	8.517	[6.714, 10.320]	<.001		
	Actor	−0.044	[−0.091, 0.002]	.060	−0.146	−0.136
	Partner[d]	−0.030	[−0.082, 0.022]	.256	−0.089	−0.079
	k	0.677	[−0.929, 2.283]			

(Continues)

TABLE 3 (Continued)

	Effect	Estimate	95% confidence interval	p	Beta(s)[a]	r[b]
General well-being						
Mothers	Intercept	12.760	[11.074, 14.447]	<.001		
	Actor	−0.140	[−0.188, −0.091]	<.001	−0.414	−0.378
	Partner[c]	0.037	[−0.007, 0.080]	.099	0.121	0.123
	k	−0.262	[−0.546, 0.022]			
Fathers	Intercept	14.885	[13.173, 16.597]	<.001		
	Actor	−0.159	[−0.203, −0.116]	<.001	−0.495	−0.456
	Partner[d]	0.004	[−0.045, 0.053]	.868	0.012	0.014
	k	−0.026	[−0.331, 0.279]			

[a]Beta(s) uses the *SD* for mothers and fathers separately.
[b]Pairwise partial correlation.
[c]Partner effect from fathers to mothers.
[d]Partner effect from mothers to fathers.
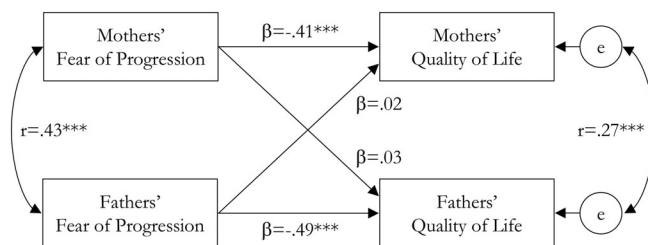
FIGURE 1 Actor-partner interdependence model (APIM) for the effect of FoP on the overall QoL with standardized parameter estimates b(s) (*** $p < .001$)

FoP on various aspects of their QoL. Therefore, health care professionals should provide appropriate support to address elevated levels of parental FoP. It is necessary to find a way to identify parents in need of psychosocial support. So far, only cut-off scores based on statistical considerations are available.[12,32] When developing new support offers, it should be considered that childhood cancer is rather rare. Thus, regionally independent support measures, such as computer-based support offers, are highly desirable.

5 | CONCLUSIONS

FoP in parents of childhood cancer survivors has not been adequately investigated yet. In this study, most parents of childhood cancer survivors reported elevated levels of FoP after the end of intensive cancer treatment. FoP in mothers and fathers was negatively associated with their own QoL but not with their partner's QoL. We also found a positive correlation between FoP in mothers and fathers of the same child. Psychosocial support is highly indicated to target dysfunctional levels of FoP in parents and to enhance their QoL after their child's cancer treatment.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Corinna Bergelt is the principal investigator of the study. Corinna Bergelt, Laura Inhestern and Mona L. Peikert developed the study concept and the design. Laura Inhestern and Mona L. Peikert developed the study materials and Mona L. Peikert, Laura Inhestern, Konstantin A. Krauth, Gabriele Escherich, Stefan Rutkowski and Daniela Kandels acquired the data. Mona L. Peikert analyzed and interpreted the data and wrote the first draft of the manuscript. All authors have revised the subsequent drafts critically for important intellectual content, approved the final manuscript to be published and agreed to be accountable for all aspects of the work.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Mona L. Peikert https://orcid.org/0000-0002-3754-7363
Laura Inhestern https://orcid.org/0000-0003-2513-7954

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.