Child and parental adaptation to pediatric oncology

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Parental stress and perceived vulnerability five and ten years after pediatric SCT

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Bone Marrow Transplantation, Nov. 2009, Nov (2) Epub

Abstract

Goals of work. The aim of the article was to evaluate parental stress, well-being and perceptions of child vulnerability, 5 and 10 years post the stem cell transplantation (SCT) of their child. *Methods.* Seventy-three parents of children and adolescents (mean age 14 years) who underwent SCT 5 or 10 years ago responded to questionnaires on general distress (GHQ), disease-related stress (PIP-SF) and perceptions of child vulnerability (CVS). *Results.* Mean general distress scores were comparable to the reference groups, but 40% of the mothers 5 years post-SCT and 21% of the parents 10 yr post-SCT reported increased stress levels as compared to the reference group. Disease-related stress was comparable to the comparison group of parents of children just off cancer treatment, 5 years post-SCT. Ten years post-SCT, scores were lower than the comparison group. Perceived child vulnerability was high in parents of SCT survivors, compared to parents of healthy children: more than 75% of all parents scored above the cut off point. Perceived vulnerability was found to be a predictor for parental disease-related stress (R^2 .57 for mothers and .63 for fathers).

Conclusions. Although most parents of SCT survivors are resilient, the majority of parents perceive their child to be much more vulnerable than parents of healthy children. These perceptions are associated with disease-related stress and may induce overprotective parenting.

Introduction

With increased survival after stem cell transplantation (SCT), attention has shifted to long-term psychological effects of SCT on survivors and their parents. Even if treatment has been successful, there is a risk of recurrence, acute or chronic graft-versus-host disease (GVHD) and late effects such as pulmonary disease, growth problems, infertility and secondary malignancies [2,12,13]. Previous research has shown that pre-SCT and during the acute phase of SCT, many parents report heightened anxiety, depressive symptoms, parenting stress and general distress, which subsides in the majority of parents between 3 and 12 months post-SCT [16,18,19,26]. Most studies have focused on parental stress and adjustment pre-SCT, during the acute phase and 12-18 months post-SCT. To our knowledge, only one –qualitative- study [6] focused on long term parental distress. Results showed that parents, 4-8 years post transplantation, still worried about late effects of treatment, the risk of secondary malignancies, infertility and their child's psychosocial well-being.

Perceptions of child vulnerability can be found in parent of children with a life-threatening illness [22]. Perceived vulnerability reflects parental attitudes or beliefs that their child is particularly vulnerable or susceptible to harm [23]. It can lead to overprotective behavior in parents and psychological problems in children, such as separation anxiety, psychosomatic complaints, impaired peer relationships and poor school results [23]. In a sample of parents of children with cancer, perceived vulnerability was found to predict child emotional adaptation (i.e. anxiety, depression) [3]. Perceived vulnerability has not been studied in parents of SCT survivors, yet.

One of the variables influencing SCT-related parental stress is socio-economic status (SES): parents from lower SES experienced higher distress throughout the SCT process [18]. Furthermore, younger mothers reported higher levels of distress than older mothers [15]. Time since SCT has been associated with parental distress: the more time elapsed since SCT, the lower the stress levels [18]. The effect of objective medical factors on parental stress levels seems to be small [4,5,19]; the subjective appraisal of these factors seems to be more predictive of parental distress. Differences between parents of children with a malignant versus a non-malignant disease have not been reported, so far.

The aims of our study were to 1) evaluate both general and disease-related parental stress and the perceived vulnerability of the child, compared with population norms, in parents whose child underwent SCT 5 or 10 years ago, 2) compare stress levels of fathers and mothers 5 and 10 years post-SCT and 3) identify which variables determine long-term parental stress post-SCT. Therefore, distress was determined with both medical and socio-demographic determinants as well as with the vulnerability perception of the parents.

Method

Procedure

The Medical Ethical Committee of the Leiden University Medical Center (LUMC) granted approval for this study. All parents of surviving children who underwent allogeneic SCT in the period 2002-2003 (5 years ago) and the period 1997-1998 (10 years ago) in the LUMC received written information about the study and were invited by letter to participate in the study, provided they had sufficient knowledge of the Dutch language. It was explained to the parents that the researchers aimed to evaluate parental stress and well-being, 5 and 10 years post-SCT. When parents gave their written consent (by returning the consent form to the researchers), they received the questionnaire booklets by mail. Parents who did not return their consent form were called to remind them and were given more information about the study, if necessary. Parents were instructed to fill in the questionnaires separately and not to consult each other. After completion of the questionnaires the parents returned the booklets by mail. Several follow-up telephone calls were placed to remind parents to fill in and return the booklets.

Measures

The *Pediatric Inventory for Parents, short form (PIP-SF)* is derived from the 42-item self-report questionnaire PIP that measures parental stress related to the serious illness of their child [21]. Each of the 15 items is rated on two 5-point scales. Parents need to respond to the items twice: the first scale assesses the Frequency of each stressor; the second scale assesses how Difficult the issue has been for the parent. Parents are asked to consider last week when responding to each item. Adequate internal consistency (α =.80-.96) and construct validity of the original and translated version of the PIP have been reported and PIP total scores have been found to correlate significantly with a general non-illness specific measure of state anxiety and parenting stress [21,25]. The original reference group of the PIP consisted of 139 parents whose child was still on treatment and 35 parents (20 mothers, 15 fathers) of children who had recently completed treatment. We decided to use this latter subgroup of parents for comparison with our sample. The PIP-SF was developed by the authors and consists of the 15 items of the full PIP with the highest item-total correlations and the highest clinical relevance. The PIP-SF Total correlated highly with both PIP-SF Frequency and PIP-SF Difficulty (.95 and .93 respectively) in our sample, hence we decided to use the PIP-SF Total scale, only. Internal consistency of the PIP-SF in our sample was .95. See the Appendix for the items of the PIP-SF.

The *General Health Questionnaire (GHQ)* 12-item version is a self-report measure of non psychotic psychiatric disorders that can be used as a general measure for psychological distress. The psychometric properties of the Dutch version of the scale are reported to be highly satisfactory [10] and the questionnaire has been used frequently in both research and clinical settings [24,27]. The cut-off score of the GHQ is 2, meaning a total score of 0 or 1 is interpreted as 'no psychological morbidity' and a score of 2 or higher is interpreted as 'possible psychopathology'. Internal consistency in our sample was consistent with previous reports (α was .86).

The *Child Vulnerability Scale (CVS)* [8] is an instrument to identify parental perceptions of their child's vulnerability. It contains 8 items with a 4-point response scale ranging from 'definitely false' to 'definitely true' scored from 0 to 3. Items include statements as 'In general, my child seems less healthy than other children'. The proposed cut-off score for the CVS is 10. The Dutch version of the CVS is available [20] and it has good reliability and validity, but the results of this study have not been published, yet. Therefore, the American reference group was used in this study [8]. Internal consistency for the current sample was .88.

Demographic and clinical information

Gender, age, marital status, educational level of the parent, as well as gender and age of the target child, the child's underlying diagnosis and the number of years since SCT were retrieved from the medical files. See Table 1.

Statistical analysis

Differences between responders and non-responders were calculated with the use of independent T-tests and chi square tests for non-parametric variables. We used Cronbach alphas to determine the reliability of our measures. One sample T-tests were performed to compare the two study groups with reference groups on general distress and perceived vulnerability. Independent T-tests were used to compare disease-related stress with available data from the subgroup of parents of children who were off cancer treatment (N=35) [25]. To determine whether the percentage of fathers and mothers scoring above a cut-off score differs significantly from the percentage of people in the reference group, we used a one-sample chi square test. Independent T-tests were performed to compare the two study groups with regards to general and disease-related stress and perceived vulnerability. All analyses were conducted for mothers and fathers, separately.

Our study groups were relatively small, hence only a limited number of variables could be included in the regression analysis. Therefore a pre-selection of the three highest correlating predictors was made. If not significant, we still added them into the model for continuity. Predictors were situational characteristics (parent age, originally Dutch (yes/no) and medical characteristics (time since SCT (in years) and malignant disease (yes/no)) per outcome subscale (total disease-related stress and general distress). Perceived vulnerability served both as an outcome and as a possible predictor for disease-related and

general stress. We accepted r > .30 as an arbitrary criterion for the selection of the variable. The analyses were performed separately for mothers and fathers, because dependence exists between the data. A combination of the most strongly related variables was entered simultaneously in the regression analysis. Firstly, the model was carried out for perceived vulnerability (CVS). Next, the model was carried out for the disease-related (PIP-SF) total score and for general stress (GHQ). For each regression analysis, the explained variance (*R square*) was determined, and it was tested using the *F*-test. T-values and their significance levels were calculated to test the hypothesis whether the contribution (the regression coefficient (*B*)) of an entered variable significantly differed from zero.

Results

Participants

In the group of 28 eligible pairs of parents 5 years post-SCT, five couples refused. Reasons for refusal were: not motivated to participate, did not want to be reminded of the SCT period, too busy with work and the fact that the SCT had been too long ago. Eight families did not return their booklets even after repeated reminders by mail and by phone. The final sample 5 years post-SCT consisted of 29 parents (15 mothers and 14 fathers) of 15 survivors, the response rate was 54%. In the group of parents 10 years post-SCT, eligible parents of 54 SCT survivors were approached. Eight families refused to participate. Three of the returned booklets were blank and were excluded and 18 families did not return their booklets. The final sample 10 years post-SCT consisted of 25 families (46% response rate), comprised of 23 mothers and 21 fathers. See Figure 1.

Non-responders consisted of significantly more non-Dutch parents (37% in the group of parents 5 years post-SCT and 21% in the group of parents 10 years post-SCT) compared to 13% and 8% percent, respectively, in the participant groups. Non-Dutch parents were defined as parents who were born outside the Netherlands. Parents in our study group were born in the following countries: Morocco, Turkey, Aruba and Surinam. The children of non-responders did not differ from the children of participating parents with respect to age and diagnosis (i.e. the percentage of malignant diagnoses). In total, parents of 82 eligible survivors were approached by letter and 73 parents (49%) consented, consisting of 38 mothers and 35 fathers. For a detailed description of the total study group, see Table 1.

Figure 1. Flow chart of participants

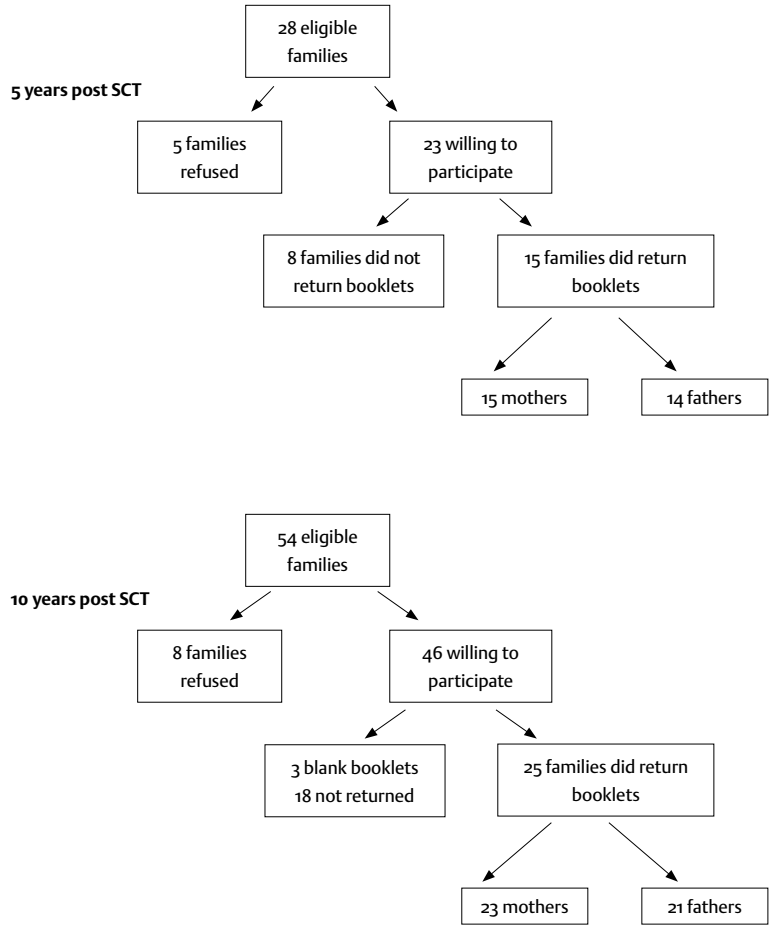

Table 1. Descriptive information about study participants and their children

Factor	*5 years post SCT (29)* *Mean (sd)*	*10 years post SCT (44)* *Mean (sd)*
Parent age (years)	44.7 (4.7) Range 37-58	46.3 (5.5) Range 39-63
	N (%)	N (%)
Parent gender		
Female	15 (55)	23 (48)
Parental education		
Primary school only	3 (10)	6 (14)
High school only	6 (21)	9 (21)
MBO	10 (35)	9 (21)
HBO	4 (14)	14 (31)
University degree	5 (17)	2 (4)
Unknown	1 (3)	4 (9)
Country of origin		
Dutch (The Netherlands)	25 (86)	36 (82)
Other	4 (14)	8 (18)
Child age (years)	13.4 (4.8) Range 5-22	16.6 (4.4) Range 11-26
Child gender		
Female	9 (53)	10 (40)
Male	8 (47)	15 (60)
	N (%)	N (%)
Diagnosis child		
ALL, AML, CML,JMML	8 (48)	14 (56)
MDS	-	3 (12)
Immune deficiency	2 (12)	1 (4)
Fanconi anemia	3 (18)	-
Other blood diseases	-	5 (20)
Metabolic disorders	-	1 (4)
X-LPD	2 (12)	-
Other diseases	2 (12)	1 (4)

MBO, Post high school education, community college level; HBO, College level;
ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia; CML, chronic myelogenous leukemia; MDS, myelodysplastic syndrome; X-LPD, X-linked lymphoprolerative disorder

Parental stress

Scores on the disease-related measure were comparable in mothers and fathers, 5 years post-SCT, compared to parents of children off treatment for cancer [25] (fathers T = 1.73, $p > .01$; mothers T = .9, $p > .01$). Scores of parents 10 years post-SCT were significantly lower than the comparison group (fathers T = 3.62, $p < .01$; mothers T = 3.20, $p < .01$).

The items of the PIP-SF with the highest scores were: '*Seeing my child sad or scared*', '*Feeling helpless over my child's condition*', '*Feeling uncertain about the future*' and '*Feeling scared that my child could get very sick or die*'. About 20% of all parents rated these situations as 'very difficult' or 'extremely difficult'.

Results on the general stress measure revealed that 10 years post-SCT, mothers and fathers did not show elevated levels of general distress, compared to population norms of the instrument (i.e. men and women in the same age group as the participants): mean scores were comparable and 24% of the parents scored above the cut-of score versus 26% in the general Dutch population with comparable ages [10]. However, one sample chi square tests showed that in the group of parents 5 years post-SCT, the percentage of mothers scoring above the cut-off (44%) was significantly higher than the percentage of women in the reference group (26%), $p < .05$.

Scores on the CVS revealed that both mothers and fathers 5 and 10 years post-SCT perceived their child to be much more vulnerable than parents of healthy children in the American community-based reference group of parents [8]. The percentage of parents with scores above the cut-off was 94 % for the group 5 years post-SCT and 76% for the group 10 years post-SCT, as opposed to 10.1 %. Mothers and fathers scored equally high. See Table 2.

Table 2. Parental stress scores of study groups and reference groups: means and standard deviations for mothers and fathers

Outcome measure	5 years post-SCT Mean (sd)	10 years post-SCT Mean (sd)	Reference group Mean (sd)
	Mothers		
	(N=15)	(N=23)	
PIP-SF Total	66.4 (28.7)	55.4 (25.6) [a,b]	74.4 (24.0)
GHQ	2.2 (3.1)	1.4 (2.2)	1.8 (0.8)
CVS	18.7 (7.6) [a]	16.2 (8.0) [a,b]	2.1 (2.5)
	Fathers		
	(N=14)	(N=21)	
PIP-SF Total	55.4 (25.6)	42.6 (15.6) [a]	69.2 (23.6)
GHQ	1.4 (2.2)	1.6 (2.2)	1.3 (0.3)
CVS	18.3 (8.0) [a]	16.2 (3.7) [a,b]	2.1 (2.4)

PIP-SF, Pediatric Inventory for Parents, short form; GHQ, General Health Questionnaire; CVS, Child Vulnerability Scale. [a] significant difference with reference group, [b] significant difference between 5 and 10 years post SCT

Differences between stress levels 5 and 10 years post-SCT

General parental stress of mothers and fathers 5 years post-SCT did not differ significantly from parents 10 years post-SCT (GHQ T = .34, *p* = .74). Perceived vulnerability was significantly higher, 5 years post SCT (CVS fathers T = 9.71, *p* =.004, CVS mothers T = 6.27, *p* =.02*)* and disease-related stress was significantly higher in mothers 5 years post-SCT (PIP-SF T = 2.52, *p*<.05) than in mothers 10 years post-SCT. For fathers, scores did not differ (PIP-SF T = 1.49, *p* =.16).

One sample chi square tests showed that in the group of parents 5 years post-SCT, the percentage of parents scoring above the cut-off (40%) on the GHQ was significantly higher than the percentage in the group 10 years post-SCT (21%). The same holds true for the percentage of parents scoring above the cut off on the CVS: 94% in the group 5 years post-SCT was significantly higher than 76% in the group 10 years post-SCT. Separate analyses for fathers and mothers reveal the following percentages above the cut off: fathers go from 92% (5 years) to 69% (10 years) and mothers go from 98% to 78%.

Correlates predictors of parental stress and perceived vulnerability

To assess the influence of time since SCT, ethnicity, underlying disease (malignant versus non-malignant) and parent age on parental stress and perceived vulnerability, we calculated Pearson correlations for mothers and fathers separately. The results are depicted in Table 3. We found that, for mothers, disease-related stress was significantly correlated with ethnicity and underlying disease. General stress and perceived vulnerability were also correlated with ethnicity. For fathers, older age was correlated with higher disease-related stress. Perceived vulnerability was correlated with ethnicity, underlying disease and paternal age. Comparisons between fathers and mothers showed that age was of influence for disease-related stress (.58) and perceived vulnerability (r .42) in fathers, but not in mothers (.13 and -.06 respectively). For mothers, whether the underlying disease of the child was malignant was significantly correlated with disease-related stress (.43). The correlation was not significant for fathers.

Predictors of perceived vulnerability and parental stress

Forced entered regression analyses, performed separately for mothers and fathers, showed that the variation in perceived vulnerability was explained by a combination of three of the following (highest correlating) variables: time since SCT, ethnicity, underlying disease and parent age. For mothers, the adjusted R^2 of the combined predictors was somewhat lower than for fathers, but this difference was not significant (.30 versus .35). Time since SCT was not predictive of perceived vulnerability.

Forced entered regression analyses showed that perceived vulnerability (CVS levels) accounted for 57% of the variance in disease-related stress (PIP-SF) in mothers and 63% in fathers. Parental age was predictive of perceived vulnerability in fathers, but not in mothers. Perceived vulnerability did not predict general stress (GHQ) for mothers or fathers. See Table 4.

Table 3. Correlation matrix between parental stress, perceived vulnerability and influencing variables for mothers (N=38) and fathers (N=35)

	PIP-SF total	GHQ	CVS	Time since SCT	Ethnicity	Malignant/non-malignant	Parent age
Mothers							
PIP-SF total	-	.44*	-.71**	.36	.56*	.43*	.13
GHQ		-	-.21	.08	.42**	.07	.02
CVS			-	-.16	-.59**	-.20	-06
Time since SCT				-	-.04	-.04	.15
Ethnicity					-	.28	-.17
Malignant/non-malignant disease						-	.0
Parent age							-
Fathers							
PIP-SF total	-	.36	-.77**	.33	.39	.27	.58
GHQ		-	-.24	.01	.30	.09	.17
CVS			-	-.15	-.47**	.33*	-.42
Time since SCT				-	-.01	-.08	.10
Ethnicity					-	.18	.04
Malignant/non-malignant disease						-	.12
Parent age							-

* correlation is significant at the 0.05 level, * correlation is significant at the 0.01 level

PIP-SF, Pediatric Inventory for Parents, short form; GHQ, General Health Questionnaire; CVS, Child Vulnerabili

Table 4. Simultaneous Regressions (Beta) for Measures of Adjustment[1]

	CVS	PIP-SF total	GHQ
	Mothers		
Adjusted R square (sign. of F)	.30*	.56**	.07
Parent age			-.09
Time Since SCT	.09		
Ethnicity (yes/no)	.56**	.15	.22
Malignant (yes/no)	-.08	.20	
CVS	-	-.57**	-.07
	Fathers		
	CVS	PIP-SF total	GHQ
Adjusted R square (sign. of F)	.35**	.66**	.07
Parent age	-.32	-.30*	-.13
Time since SCT			
Ethnicity (yes/no)	-.39**	-.02	.06
Malignant (yes/no)	-.25		
CVS	-	-.63**	-.27

[1]values reported are standardised regression coefficients (Beta) with significance of *t*, with the exception of the rows presenting *Adjusted R squares* with significance of *F*. * $p < 0.05$ ** $p < 0.01$
CVS = Child Vulnerability Scale; PIP-SF= Pediatric Inventory for Parents, short form; GHQ = General Health Questionnaire

Discussion

Having a child who needs to undergo stem cell transplantation is a stressful event for any parent. Our study revealed that, ten years after SCT, most parents have reached normal levels of general distress and disease-related stress, compared to the reference groups. However, five years post-SCT, 40% of the mothers still score above the cut-off score on the general stress measure. Five years post-SCT, disease-related stress was comparable to parents of children who had recently ended cancer treatment, both in mothers and in fathers. Furthermore, a large percentage of all parents (more than 75%) in our study group still perceive their child to be much more vulnerable than other children. This finding is understandable, given the life-threatening illness of their child in the past, the intensive and stressful SCT-procedure their child had to undergo and the possible late effects.

Regression analyses showed that perceived vulnerability was predicted primarily by ethnicity; underlying disease, time since SCT and parent age played a minor role. High perceived vulnerability could be a reflection or result of chronic strain or even burnout in parents of SCT survivors. In a recent study among parents of brain tumor survivors -a group of survivors with possible sequelae, just like SCT-survivors-, more than half of the mothers reported to have burnout symptoms, consisting of emotional exhaustion, physical fatigue and cognitive difficulties [17]. Strain does not have to be traumatic or severe to have high psychological impact. Even low-intensity stressors may create a severe effect, if they are long-lasting or recurrent [17].

Parental disease-related stress was predicted primarily by perceived vulnerability and paternal (not maternal) age. Furthermore, even though the percentage of non-Dutch parents was low in our sample, we found a significant correlation of ethnicity with disease-related stress and perceptions of child vulnerability. Parents from an ethnic minority have reported higher general stress levels before in different illness populations [9], possibly due to a lack of resources and social support. For mothers, underlying disease (malignant or not) was related to disease-related stress. For fathers, whether the underlying disease was malignant or not was related to perceived vulnerability. Parents of children with a malignant disease are usually faced with more stress before SCT than parents of children with a non-malignant disease, due to lengthy periods of treatment with chemotherapy and -in many cases- having to deal with the shock of a relapsed disease. These prior illness experiences influence parental stress levels during and after the SCT trajectory [19]. Furthermore, it has been found that post-SCT, the psychosocial impact of late effects is higher in children with a malignant disease [14]. The child's health post-SCT is found to have a significant impact on parental emotional functioning [7]. Furthermore, the fear of another relapse, sometimes referred to as the Damocles syndrome' [1,11], can be present in both cancer survivors and their parents for a long time.

Limitations of the present study are the relatively low number of participants and, more specifically, the low response rate. Because of the variety in reasons for non-participation, it is difficult to tell whether this leads to under- or over reporting of parental stress levels. The manner in which the study was conducted, namely by mail only, can lead one to speculate that only the families that were doing well responded and therefore that the study might not be representative of this population. It is not easy to conduct research with families for whom SCT has taken place so long ago, because some parents want to put the whole experience behind them and others feel that it is no longer relevant to report on their own well-being after so many years. Furthermore, the study was single-centered, meaning results are more difficult to generalize to other medical centers. We did manage to include a large percentage of fathers in our study.

Lastly, although disease-related measures can render important information on the reactions of parents to the specific situations that having an ill child might bring, a major limitation of these instruments is the lack of an adequate comparison group, since these measures have not been used in a population of parents of healthy children. In the present study, we compared our findings on the disease-related measure (PIP-SF) with a group of Dutch parents whose children had just come off treatment for cancer, knowing that there are differences between the two groups regarding the frequency of hospital visits and worries about immediate and late effects of treatment. Furthermore, the present study group also consisted of parents whose children had a non-malignant disease. However, we did find that the perceived difficulty of some of the disease-related situations (mostly worrying about the child's health and future) is still relatively high in a subset of parents of SCT patients.

The authors conclude that most parents of SCT survivors are resilient and do not report heightened stress scores, compared to reference groups. Mothers are more prone to general stress, 5 years post-SCT. Perceptions of child vulnerability are high in this group of parents and this could lead to overprotective parenting behavior. We recommend more in-depth qualitative studies on the experiences of parents who are from another cultural background and long term psychosocial screening in parents of SCT survivors who are at risk for long term stress, alongside with the existing late effects clinics. Post-SCT care could involve group counseling and referrals to individual counseling in the parents' own environment if necessary.

Acknowledgements

We would like to thank all participating families for their willingness to cooperate in this study. Furthermore, we owe many thanks to graduate students Marjolein Littooij and Renée Elaine Veldhuis for their contribution to this research project.

Appendix. Item-total and item-scale correlations of the PIP short form scales

Items	Corrected Item-Total Correlation Frequency	Corrected Item-Total Correlation Difficulty
1 (5)*. Being unable to go to work/job	.61	.56
2 (7). Speaking with doctor	.65	.40
3 (13). Being with my child during medical procedures	.72	.59
4 (16). Seeing my child sad or scared	.72	.62
5 (17). Talking with the nurse	.63	.66
6 (18). Making decisions about medical care or medicines	.62	.41
7 (25). Having little time to take care of my own needs	.71	.55
8 (26). Feeling helpless over my child's condition	.69	.49
9 (28). Handling changes in my child's daily medical routines	.58	.53
10 (29). Feeling uncertain about the future	.70	.59
11 (30). Being in the hospital over weekends/holidays	.69	.64
12 (33). Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing)	.61	.56
13 (36). Feeling scared that my child could get very sick or die	.65	.40
14 (38). Watching my child during medical visits/procedures	.72	.59
15 (42). Spending a great deal of time in unfamiliar settings	.72	.62

*The numbers between brackets refer to the item numbers in the original questionnaire.

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