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Disease-related Parenting Stress in the Post-treatment Phase of Pediatric Cancer

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ABSTRACT

Parenting stress is generally associated with poorer psychological adjustment in caregivers and children with chronic illness. Although parenting stress in pediatric cancer has been previously demonstrated, few studies have investigated this problem when treatments end. The present study aimed to describe disease-related parenting stress in the post-treatment phase of pediatric cancer, and to analyze the role of parents' age and education, family functioning, and perceived child vulnerability in predicting disease-related parenting stress. The study comprised 56 parents of children with cancer, in the post-treatment phase, who completed a clinical and demographic questionnaire, as well as the Pediatric Inventory for Parents, assessing parenting stress, the Child Perceived Vulnerability Scale, and the Family Adaptability and Cohesion Evaluation Scale-Version IV. Results revealed that the level of disease-related parenting stress in the post-treatment phase was still significant. Emotional stress scores were especially high, further showing that parents' concerns in this phase focus mainly on the long-term impact of the disease and treatments, involving intense feelings of fear and uncertainty. A model with four predictors was tested using regression analysis, which explained 57% of parenting stress variance. More specifically, findings indicated that parental age and education significantly predicted parenting stress, accounting for over one-third of the variance in this outcome. Family functioning and perceived child vulnerability explained an additional 18% of parenting stress. Findings of this study suggest that even when treatment ends, there is still the need for continued support in order to assist parents' ability to deal with the implications of having a child who had cancer. Importantly, special attention should be given in clinical practice to the family functioning and to parents' beliefs about their child's vulnerability.

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Introduction

Pediatric cancer is an overwhelming event that negatively affects children and adolescents, as well as their caregivers. Due to the significant increase in cancer survival in pediatrics in the past decades, nowadays having a diagnosis of cancer means living with a chronic and complex condition (American Academy of Pediatrics Section on Hematology/Oncology Children's Oncology, 2009). As such, the experience of pediatric cancer is full of experiences of suffering, and involves the exposure to many stressors, such as repeated intrusive procedures, frequent hospitalization, isolation, immobility, and restriction of normative life activities, that sometimes persist after the end of treatments. Thus, children and their parents are particularly exposed to stress and susceptible to emotional disturbances (Bemis et al., 2015; Molinaro & Fletcher, 2017; Okado, Tillery, Sharp, Long, & Phipps, 2016; Schepers et al., 2018; Tsai et al., 2013; Vrijmoet-Wiersma et al., 2010).

In the presence of a chronic illness, parents are prone to experience both personal distress and parenting stress (Driscoll et al., 2018). Although they are sometimes used indistinctively, the first describes psychological suffering expressed through depression, anxiety and posttraumatic stress symptoms (Norberg & Boman, 2008), and the second is used to describe an emotional strain that is directly related to the role and tasks of being a parent, in this case, of an ill child. Thus, in this particular study, and since the focus is on the stress induced by the burden of caring for a child with cancer, the term disease-related parenting stress is used.

Parenting stress in pediatric cancer has been extensively demonstrated (Bennett, English, Rennoldson, & Starza-Smith, 2013; Golfenshtein, Srulovici, & Medoff-Cooper, 2015; Haegen & Luminet, 2015; Okado et al., 2016; Schepers et al., 2018). Parents of children with cancer suffer from higher levels of stress when compared to other groups, namely parents of healthy children (Cousino & Hazen, 2013; Masa'Deh, Collier, & Hall, 2012; Schepers et al., 2018) and parents of children with other chronic illnesses, such as congenital heart diseases and autism spectrum disorders (Golfenshtein et al., 2015).

Studies that explore whether parenting stress changes along the course/trajectory of the disease/treatment frequently indicate that the time surrounding the diagnosis is the most critical, and that parenting stress tends to diminish following treatment (Fedele, Mullins, Wolfe-Christensen, & Carpentier, 2011; Norberg & Boman, 2008; Tsai et al., 2013). However, only a few studies have focused on long-term disease-related parenting stress (Boman, Lindahl, & Bjork, 2003; Norberg, Lindblad, & Boman, 2005). The existing longitudinal research has shown that disease-related parenting stress can last 5–10 years after completing the treatment (Vrijmoet-Wiersma et al., 2010). In a systematic review by Price, Kassam-Adams, Alderfer, Christofferson, and Kazak (2016), results showed that 40% to 83% of parents of children with cancer experience distress during the first month after the diagnosis. However, 6 months after the diagnosis, these numbers decrease by 18% to 30%, and by another 7% to 22%, 10 months after the diagnosis.

Nevertheless, there is also some evidence that disease-related parenting stress does not always decrease over time (Bennett et al., 2013; Sloper, 2000) and that a subset of parents continue to suffer from significant stress years after the treatment has been completed (Norberg et al., 2005). In a study by Vrijmoet-Wiersma, Egeler, Koopman, Norberg, and Grootenhuis (2009), the parents who were most at risk in the longer term were those who displayed the highest levels of stress during treatment.

One important research goal is to identify sources of parenting stress throughout the various phases of pediatric cancer. Such knowledge is essential in order to develop interventions aimed at reducing parenting stress and promoting coping strategies among families. During the active phase of the illness, the sources for parenting stress are usually related to clinical factors, such as medical exams and treatment side effects, and to the parents' perception of the child's suffering and pain (Alves, Guirardello, & Kurashima, 2013; Molinaro & Fletcher, 2017). Later on, parents begin to worry about the inefficacy of treatments, the possibility of relapse and death (Alves et al., 2013), as well as the effects of treatments in the future (Vrijmoet-Wiersma et al., 2010).

Given the importance of parenting stress to the psychological adjustment of children and caregivers, it is important to identify the factors that aggravate or alleviate disease-related parenting stress. Parenting stress has been associated with several factors, namely factors related to parents' sociodemographic characteristics, beliefs, and family functioning.

Concerning sociodemographic variables, in general, mothers more frequently experience higher levels of parenting stress compared to fathers (Skreden et al., 2012) and this gender difference is also found in parents of children with cancer (Pai et al., 2007; Svavarsdottir, 2005). Parents' age was also proved to be a significant predictor of parenting stress in the presence of a pediatric chronic disease, with younger parents reporting higher levels of distress than older parents (e.g. Alves et al., 2013; Horsch, McManus, Kennedy, & Edge, 2007; Masa'Deh et al., 2012). Furthermore, socio-economic status influences pediatric-related parenting stress, with parents from a lower socio-economic status experiencing higher levels of distress (e.g. Phipps, Dunavant, Lensing, & Rai, 2004).

Other contextual factors, such as family functioning, influence parents' psychological reactions to pediatric illness. Recent studies have confirmed the crucial role of family context, although there is limited research in this area.

Family functioning has been specifically associated with the level of stress experienced by parents of children with cancer (Hosoda, 2015; Masa'Deh et al., 2012; Pai et al., 2008; Sloper, 2000). The construct of family functioning refers to many dimensions of family relations, such as communication, affection, family satisfaction, cohesion, and flexibility (Olson, 2011). It is expected that, in the presence of a serious illness such as pediatric cancer, families will need to cope with many challenges, among them emotional instability, new and demanding roles, as well as different ways of communicating effectively (Van Schoors et al., 2017). In a study by Streisand, Kazak, and Tercyak (2003), increased pediatric parenting stress was found to be associated with poorer family functioning outcomes.

Perceived child vulnerability refers to parental beliefs or attitudes toward their child's health or susceptibility to illness/harm. Research has shown that perceived child vulnerability is higher in parents of children with a life-threatening illness (Thomasgard & Metz, 1995) and that it is associated with disease-related parenting stress (Vrijmoet-Wiersma et al., 2010). In a study with parents of stem cell transplant (SCT) survivors, perceived child vulnerability was found to decrease over time, but remained high compared to parents of healthy children. The results showed that 96% of the parents at 5 years after SCT and 76% of the parents at 10 years after SCT still scored above the cut-off point (Vrijmoet-Wiersma et al., 2010). These perceptions tend to be associated with overprotective behavior in parents which can lead to psychological problems in children (Hullmann et al., 2010).

To date, few studies have explored the role of these variables on parenting stress in the post-treatment phase. Thus, the current study sought to contribute to the existing knowledge about the psychological adaptation of families in this phase of pediatric cancer, which may be important to the development of nursing and psychological interventions.

More specifically, this study will:

(1) Describe disease-related parenting stress in the post-treatment phase of pediatric cancer, specifically the level of parenting stress and the main areas of concern.
(2) Analyze the role of parents' age and education, family functioning, and perceived child vulnerability in predicting disease-related parenting stress.

Method

Participants

The study was conducted in the pediatric services of two central hospitals of the District of Porto. The inclusion criteria were being a Portuguese-speaking parent of a child or adolescent with cancer, in post-treatment phase (3 months to 5 years after the end of treatment). Post-treatment was defined as the phase when signs and symptoms have partially or totally disappeared and children are off treatment.

A total of 56 parents (39 mothers and 17 fathers) participated in the study.

Procedures

The study was approved by the institutional ethics review boards of the two hospitals. Eligible parents were previously identified by doctors and nurses and contacted by the researcher to present the relevance and the objectives of the present study. All parents who agreed to participate were taken to a more private location in the department, and were asked to complete a consent form, a clinical and demographic questionnaire, as well as the self-report measures.

Measures

Pediatric Inventory for Parents

The Pediatric Inventory for Parents (PIP) (Streisand, Braniecki, Tercyak, & Kazak, 2001) assesses the level of stress experienced by parents of children with serious illnesses. The instrument is a self-report rating of stress related to the caretaking of a child with an illness. It consists of 42 items grouped into four domains: communication (9 items), emotional functioning (15 items), medical care (8 items), and role function (10 items). Answers are given on a Likert scale of 5 points (1 – not at all to 5 – extremely), which measures the frequency and difficulty (two subscales) of an event during the previous week, as experienced by parents. In this study, only frequency was assessed and the PIP rating was calculated as a total sum for each of the four areas, with higher scores indicating higher frequency of situations generating stress experienced by parents.

Previous studies have demonstrated the validity and reliability of the Portuguese version of PIP (Dos Santos, 2009; Fontoura, 2014). In this study, internal consistency was strong for the total scale (.94) and acceptable for each of the four subscales (≥.80).

Family Adaptability and Cohesion Evaluation Scale-Version IV

The Family Adaptability and Cohesion Evaluation Scale-Version IV (FACES-IV) was developed by Olson (2011). The FACES-IV is a self-report measure, consisting of 62 items, developed to evaluate adaptability and cohesion dimensions in family interactions. The instrument has a Total Ratio that provides a summary of a family's functioning. The higher the ratio score is above 1, the more functional the family is. Conversely, the lower the ratio score is below 1, the less functional the family is. The FACES-IV is a self-report instrument. The items are statements to which the parents respond saying how much they think these statements describe their family, on a Likert-scale of 5 points (0 = No, 2 = Little, 3 = Partly 4 = In general, 5 = Much). The Portuguese-language version adaptation of FACES-IV (Gomes, Peixoto, & Gouveia-Pereira, 2017; Silva, 2015) demonstrated that the FACES-IV is reliable and valid. Reliability analysis in our sample revealed α = .86 for the total ratio of the scale.

Child Vulnerability Scale

The Child Vulnerability Scale (CVS) (Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996) was developed to measure parental perceptions of their child's vulnerability. Items ask the parent to assess their child's health in comparison to other children (e.g. "In general, my child seems less healthy than other children"). In the present study, the eight items of CVS are rated on a 4-point scale ranging from "definitely false" to "definitely true," where higher scores indicate increased parental perception of child vulnerability. The proposed cut-off score for the CVS is 10. The scale was validated to the Portuguese population (Lima, Lemos, & Lopes, 2018), confirming that the items defining vulnerability were unidimensional and reliable (Cronbach's alpha coefficient was .86).

Statistical analysis

IBM SPSS Statistics version 24.0 (IBM, Inc., Armonk, NY, USA) was used for data analysis. Descriptive analyses were calculated for sociodemographic variables, parenting stress, parental perception of child vulnerability, and parental perception of family functioning. Correlation coefficients (Pearson's r) were used to analyze associations between variables. To explore the role of demographic variables, family functioning, and child vulnerability perception in the variance in pediatric parenting stress, a hierarchical multiple regression analysis was performed, with the PIP Total Score as the dependent variable. A p level of .05 was used for all statistical tests.

Results

Demographic characteristics

Participants were 56 parents (39 female and 17 male), between 30 and 57 years of age (M = 41.96, SD = 5.6), of 56 children and adolescents (26 are female and 30 male) with cancer in post-treatment phase (1–5 years after the end of treatment).

The majority of the participants were married with low schooling level, since most parents (n = 35; 63%) only completed 4–9 years of schooling (Table 1). The children were aged between 5 and 19 years old. Regarding the type of diagnosed cancer, leukemia and lymphoma were the most frequent (41% and 21%, respectively). At the time of the study, 39% of children were in the first year after the end of treatment, 18% in the second year, 12% in the third year, 14% in the fourth year, and 18% in the fifth year.

Table 1. Demographic characteristics.

	N	%	M	SD
Parents' characteristics				
Female	39	69		
Male	17	31		
Age (in years)			41.96	5.60
Marital status				
Married	42	75		
Unmarried	14	25		
Education				
Fourth grade	17	30		
Ninth grade	18	33		
High school	13	23		
Bachelor/Master	8	14		
Children's characteristics				
Female	26	46		
Male	30	54		
Age				
5–11 years old	30	54	11.88	3.90
12–19 years old	26	46		
Diagnosis				
Leukemia	23	41		
Lymphoma	12	21		
Wilms' tumor	2	4		
Neuroblastoma	1	2		
Sarcoma	3	5		
Others	15	27		
Time since the end of treatments (in years)			2.53	1.55

Disease-related parenting stress in the post-treatment phase

The first objective was to characterize disease-related parenting stress in the post-treatment phase, more specifically the level of parenting stress and the main areas of concern. Descriptive statistics are summarized in Table 2, also including scores on parents' perceptions about child vulnerability and family functioning.

Results from the PIP evidenced medium levels of stress for the total coefficient (with 34% of the parents reporting stress levels above the mean score of the scale, and 8% above the upper quartile), and for each of the four subscales (Communication, Medical care, Role function, and Emotional functioning). The calculation of mean scores for each subscale revealed a higher level of parenting stress in emotional functioning than in the other areas.

The items from the PIP with the highest scores, which are listed in Table 3, were all included in the emotional distress domain and about 40% of all parents rated these stressful situations as "very stressful" or "extremely stressful."

Descriptive statistics of FACES-IV and CVS

Descriptive statistics of FACES-IV and CVS were calculated, indicating that the functioning of the families from this study sample is globally healthy (M = 1.89, SD = .58). In relation to perceived child vulnerability, the results

Table 2. Descriptive statistics.

	Subscale	M	Mean score	SD	Range	Min–Max
PIP frequency	Communication	20.62	2.29	6.01	10–36	9–45
	Medical care	20.38	2.55	6.31	10–34	8–40
	Emotional functioning	43.06	2.87	10.57	21–63	15–75
	Role function	22.50	2.25	7.00	12–41	10–50
	Total	106.56		26.91	58–172	42–210
Family functioning		1.89		.58	.86–3.31	
CVS		16.18		4.96		

Table 3. Items from PIP with the highest scores.

	PIP frequency	
Items	*M*	*SD*
Thinking about other children who have been seriously ill	4.11	.92
Worrying about the long term impact of the illness	3.62	1.27
Feeling uncertain about the future	3.55	1.17
Feeling scared that my child could get very sick or die	3.52	1.41

revealed that 77% of the parents scored above the cut-off point, suggesting that they believe their child is more vulnerable compared to other children of the same age. The item that scored highest was: “I often check on my child at night to make sure that she/he is okay.”

Predictors of parenting stress

The second objective was to identify the role of parents’ age and education, family functioning, and perceived child vulnerability in predicting parental stress.

First, the association between parenting stress and each of the other variables was studied using Pearson’s *r* (Table 4). Results revealed that both the total parenting stress scale as well as the four subscales were significantly associated with parental educational level, parents’ perception of child vulnerability and family functioning. Parents’ age was only associated with the role function subscale and the total scale of PIP.

The results from a multiple regression using a hierarchical (blockwise entry) method are summarized in Table 5. Two blocks were entered into the hierarchical regression. Known predictors were entered first into the model (parental age and education). These variables were selected based on theory and previous research evidence (e.g. Alves et al., 2013; Bemis et al., 2015). Subsequently, the new predictors were added into the model (family functioning and perceived child vulnerability). Parental age and education explained 38% of the variance in parenting stress. After entering family function and parents’ perception of child vulnerability in step 2, the total variance explained by the model as a whole was 56.7%, F(4, 43) = 14.06, $p < .000$. The two variables, family functioning and perceived vulnerability, explained an additional 18% of the variance in parenting stress, after controlling for parental age and education, *R* squared change = .18,

Table 4. Association between variables.

	Parents' educational level	Parents' age	Child Vulnerability Scale	FACES total
PIP–Communication subscale	−.458**	−.217	.524**	−.454**
PIP–Medical care subscale	−.452**	−.129	.415**	−.423**
PIP–Role function subscale	−.450**	−.317*	.541**	−.516**
PIP–Emotional function subscale	−.377**	−.231	.516**	−.413**
PIP frequency–Total scale	−.595**	−.304*	.603**	−.545**

*<.05; **<.01.

Table 5. Summary of hierarchical regression analysis for variables predicting parenting stress.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*B*
Parental age	−1.029	.55	−.22	−1.028	.47	−.22
Parental education	−13,739	.2,9	−.56	−7.780	.2.9	−.31
Family functioning				−11.057	.5.26	−.25
Perceived vulnerability				1.814	.62	.33
R^2		.384			.567	
		14.052**			9.046**	

**<.01.

F change (2, 43) = 9.05, $p < .001$. In the final model, all four variables were statistically significant, with perceived vulnerability recording a higher value ($\beta = .33$, $p < .005$) than the other three variables.

Discussion

The present study was designed to describe disease-related parenting stress in the post-treatment phase of pediatric cancer and to determine the relative contribution of parent's sociodemographic variables (age and education), family functioning, and perceived child vulnerability, on parenting stress in the post-treatment phase.

The findings show that the level of disease-related parenting stress in the post-treatment phase was still significant. Whereas no available research provides directly comparable results on parenting stress in the post-treatment phase, it is interesting to note that the level of parenting stress found in this study seems to be consistent with the levels of stress that have been reported in other studies during the treatment phase (Bennett et al., 2013; Boman et al., 2003). The findings of this study further support the idea that, when treatment ends, disease-related parenting stress levels do not appear to decrease significantly, at least for a subgroup of parents (Bennett et al., 2013; Norberg et al., 2005).

Regarding specific domains of disease-related parenting stress, the results of the present study show higher levels for emotional stress. In this domain, parents mainly pointed out concerns about the long-term impact of the disease and treatments, involving feelings of fear and uncertainty regarding the possibility of recurrence and the long-term effects of the cancer treatment. These concerns are similar to those reported in previous studies in the post-treatment period (McKenzie & Curle, 2012; Sloper, 2000), especially in a study undertaken in Brazil, also using the PIP, but during the treatment phase (Alves et al., 2013). Indeed, these concerns have a realistic base, since, although treatments are now less aggressive than a few decades ago, occasionally it is still difficult to balance oncologic efficacy and toxicity, and survivors may still experience late effects such as cardiac fatigue, neurocognitive impairments and even subsequent cancers (Song & Fish, 2018). An interesting result, which was also found in the study with Brazilian parents, was the particularly high score obtained in the item "thinking about other children who have been seriously ill". A possible interpretation, yet speculative, may be that when thinking about other ill children, parents feel that cancer and other serious pediatric conditions are common events, and thus perceive their child's condition as a bigger threat than if it were a rare phenomenon.

Findings from this study also indicated that parental age and education significantly predicted parenting stress, accounting for about one third of the variance in this outcome. These results are in line with previous research on parental adjustment to child cancer that demonstrates the role of several sociodemographic variables in the levels of stress experienced by parents (Bemis et al., 2015; Vrijmoet-Wiersma et al., 2010). Parents with lower levels of education showed significantly higher levels of parenting stress. This variable, which is an indicator of parents' literacy and an indirect indicator of the socioeconomic status of the family, seems to have an important role in communicating with health professionals and understanding the medical condition (Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005), as found in this study. The ability to comprehend the clinical aspects of the condition and the possibility to communicate more effectively with health professionals likely gives parents a greater sense of control over the situation, and facilitates decision making when managing problems related to parenting in the presence of cancer.

Age was also a significant predictor, with younger parents showing more disease-related parenting stress. Once again, this result is consistent with the study by Alves et al. (2013) and is likely explained by less parenting experience in younger parents. The correlational results showed that age is mainly associated to parents' level of emotional distress, which reinforces the idea that lack of experience may lead them to feel insecure and, thus, more prone to emotional distress, as also claimed by Alves et al. (2013).

Family functioning and perceived child vulnerability also play a significant role in explaining the parenting stress experienced by parents of children who are in the cancer post-treatment phase.

Regarding family functioning, it is important to note that the results highlight a resilient trajectory, since families were characterized by adaptive functioning. Moreover, family functioning impacted parenting stress. Other studies with families of children with oncological disease had already suggested this influence (Hosoda, 2015; Masa'Deh et al., 2012; Pai et al., 2007). This means that there is a significant likelihood of good family functioning representing less stress and poor family functioning increasing parenting stress levels in pediatric chronic illness (Yamaguchi et al., 2018). In a recent meta-analysis (Van Schoors et al., 2017) dimensions of family functioning such as positive emotional bonding, open family communication, and the ability to resolve conflicts were associated with family adjustment and resilience after pediatric cancer diagnosis.

Scores on perceived child vulnerability revealed that, in the post-treatment phase of pediatric cancer, parents still perceived their child as vulnerable, when compared with parents of healthy children. Since there are no published Portuguese norms on the CVS, this study adopted an American community-based reference group to compare the percentage of parents that classified their children as vulnerable (Forsythet et.al., 1996). The percentage of parents with scores above the cut-off point was 77% in the present study, as opposed to 10.1% for all parents in a community sample (Vrijmoet-Wiersma et al., 2010). These results are similar to those obtained in previous research with parents of children who underwent SCT (Mullins et al., 2007), showing strong lasting effects. In the long run, perceived child vulnerability tends to lead to overprotective parenting, which may lead to psychosocial problems in children (Thomasgard & Metz, 1995).

As found previously, specific cultural variables such as origins, religion, and traditions affect the family's adjustment to a chronic illness as cancer (Perricone et al., 2013). As such, cultural specificities are very likely to affect the level and focus of parenting stress as well as the variables that interact to facilitate or hinder parents' adjustment. Therefore, future cross-cultural research could be usefully explored to establish the generalizability of the present findings to different countries.

Conclusions

The current study provides new insights into the level of disease-related parenting stress in the post treatment phase of pediatric cancer, showing that even when treatment ends, parents still experience significant levels of stress, mainly in the area of emotional functioning. Findings of this study offer sound support to the hypothesized model comprising four variables (parent's age and education, family functioning, and perceived child vulnerability) which explained 57% of the variance in parenting stress.

The present results have important implications for the development of nursing interventions aimed toward supporting parents in coping with a child with cancer after treatment ends. Firstly, since age and education were found as significant predictors of parenting stress, they allow to identify parents who are particularly at risk for disease-related parenting stress. Therefore, nurses and other health professionals should be especially attentive to younger parents and to those with lower educational levels.

Secondly, the findings also offer contributions to the development of nursing interventions aimed toward facilitating parents' adjustment to pediatric cancer. In line with recent conceptualizations of pediatric chronic illness, interventions should aim to address variables that are important resources to parenting capacities. An important focus of attention is family functioning, as it also seems to act as a resource for facing a serious illness such as cancer. Parents' beliefs about their child's vulnerability were also found as a significant predictor, and nurses may play an important role, not only in helping parents to evaluate their child's health in a more positive way, but also to acquire knowledge and skills that will help them feel more able to assist their child's needs and, indirectly, also feel more secure at an emotional level.

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