

Mothers and fathers of children with cancer: loss of control during treatment and posttraumatic stress at later follow-up

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Abstract

Background: A child's cancer can lead to changes in parental role functioning, including loss of control. We studied the extent to which parental perceived loss of control during a child's cancer treatment predicted posttraumatic stress symptoms (PTSS) after completion of treatment.

Method and participants: The sample of this longitudinal study included 62 parents (36 mothers and 26 fathers) of children currently in treatment for malignant disease (T1) and after completion of treatment (T2). Loss of control was assessed at T1 using a self-report measure, that is the loss of control module of the Parental Psychosocial Distress-Cancer questionnaire. PTSS were assessed at T2 using the Impact of Event Scale-Revised. Main analyses were carried out for mothers and fathers separately.

Results: The majority of the parents, 55% ($n = 34$), reported loss of control on more than half of the assessed domains. Only 5% ($n = 3$) reported no loss of control whatsoever. At T2, some degree of PTSS was reported by 89% ($n = 55$). These outcomes were similar for mothers and fathers. Loss of control at T1 predicted stronger PTSS at T2 primarily among mothers.

Conclusion: The experience of loss of control during cancer treatment is a salient risk factor for later PTSS in mothers. The situational threat to the regular parental role is discussed as an explanation to this observation. Interventions should address informational needs, parent participation in care, and professional support to maintain a sense of control and functioning in their parental role.

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Introduction

Most parents of children with cancer want to take an active part in the treatment-related care of their children [1]. They are also encouraged to take part in decisions about their children's treatment. When it comes to the day-to-day care, parents may be better than professionals at judging their children's pain [2], yet parents are dependent on the medical staff for the relief of their children's pain. Furthermore, parents often have insufficient knowledge to evaluate decisions about treatment at the time of diagnosis [3]. Although parents wish to have control over such judgements, they often prefer to have a collaborative or even passive role instead of being the ones who make the final decision about their children's treatment [1]. In conclusion, active participation in the intense treatment scheme influences parents' everyday life by restricting their autonomy and sense of control [4].

For parents, the knowledge of the fatality of the disease constitutes a potentially traumatic stressor [5], and parenting a child in treatment for cancer involves an array of potentially stressful events [6]. For the past decade of paediatric psycho-oncology research, there has

been a marked interest in detecting cancer-related post-traumatic stress symptoms (PTSS) among parents of childhood cancer survivors. Several studies have examined posttraumatic stress symptomatology as expressed by the core symptoms intrusions, avoidance, and hyperarousal [7,8]. Frequently, a composite measure of symptoms is presented. Normally, reactions of traumatic stress can be expected among parents within the first months of the child's cancer treatment [8–10]. In addition, severe PTSS have been reported for 10–15% of parents, years after successful completion of treatment [7,8].

Together with the fact that mothers tend to be primary caregivers of their ill children and therefore, perhaps, more readily convenient research subjects, an assumption that mothers are more affected by cancer in their children may account for why many studies still focus solely on mothers. However, although mothers indeed have been found in some studies to report more traumatic stress than fathers [11,12], other studies report equal levels of traumatic stress in mothers and fathers [7,13]. Thus, the picture appears complex and determined by several factors that, in possible combination with gender, influence parental reactions [14].

In summary, a review of the literature shows that factors such as female gender, educational status, previous history of psychiatric disorder, having a child with poorer prognosis, trait anxiety and coping style, and time passed since diagnosis may influence parental vulnerability for distress and PTSS in particular [11,13,15,16]. Additional predictors of distress symptoms are yet to be identified, as parental psychological vulnerability is likely to be multi-factorially determined. One such factor is a feeling of loss of control. Low control combined with high demands typically lead to an accentuation of strain [17]. Moreover, feelings of helplessness during a traumatic experience and low control over the trauma have been found to strongly predict the development of PTSS [18,19]. In the present study, loss of control was defined in relation to family and everyday life as feelings of negative change that were a result of the child's disease. These feelings, as addressed by a self report questionnaire, included different domains of control, for example control of everyday occurrences, social relationships, emotional experiences, financial conditions, and daily life situations.

Thus, the identification of risk factors is crucial for the development of adequate interventions aimed at preventing PTSS among parents of children with cancer. Yet, the relationship between parents' perception of loss of control and later PTSS has, to our knowledge, not been investigated. Therefore, the aim of this study was to analyse this relationship. We hypothesized that stronger feelings of loss of control during a child's cancer treatment would predict higher levels of PTSS after completion of treatment. PTSS were assessed within the three symptom clusters of post-traumatic stress disorder: intrusive thoughts or flashbacks of the traumatic event, avoidance of reminders of the event, and increased arousal.

Method

We used a longitudinal design where each parent was assessed by self-report questionnaires on two occasions. The first period of data collection (T1) occurred while the child was undergoing cancer treatment, and the second period (T2) took place after the child had completed treatment. Data collection was carried out between February 1999 and January 2005 at the Childhood Cancer Research Unit at the Astrid Lindgren Children's Hospital in Stockholm, Sweden. The study was approved by the regional ethics committee, and participation was preceded by informed consent from all parents.

Participants

The study sample included 62 parents (36 mothers and 26 fathers) of children diagnosed with malignant disease and in curative treatment (at T1). As questionnaires were in Swedish, parents who could not read or write Swedish were excluded from inclusion in the study. In

the study sample, 13 were parents of children with leukaemia, 6 with lymphoma, 4 with central nervous system tumour, 7 with neuroblastoma, 8 with Wilms' tumour, 10 with bone tumour, 9 with soft-tissue sarcoma, 4 with germ-cell neoplasm, and 1 with a hepatic tumour. The distribution of diagnoses of the children was similar among responders and non-responders. The data were collected as part of a larger study investigating the psychosocial situation of parents of children with cancer. Mean time from cancer diagnosis to assessment at T1 was 3.5 months ($SD=2.5$) with a range of 2 weeks to 8 months. One to three years elapsed between T1 and T2 (mean 20.6 months, $SD=2.5$ years).

The response rate at T1 was 73%. Of those who were eligible for a second assessment, the response rate at T2 was 82%. T1 took place within the first 8 months after initiation of the child's cancer treatment, and T2 after completion of treatment. Less than half (42%) of the responders were fathers, while fathers comprised 59% of the non-responders. At T1, the age of the participating parents ranged from 27 to 62 years (mean 41, SD 8); 41% of them were educated at the university level, and 90% had more than one child. Sixteen per cent of the participants were born outside of Sweden.

Data collection

To enhance response rate, parents were, whenever possible, invited to join the study in person by one of the authors or by a research nurse. This could be done in case the child was undergoing treatment or visiting the hospital for a scheduled clinical follow-up visit at the time for invitation; otherwise, parents were informed and invited by phone or mail. Parents were provided the questionnaires along with written information about the study. Both mothers and fathers of the approached families were asked to complete the questionnaires and to do so independently of each other. The completed questionnaires were returned by mail in a pre-paid envelope.

Assessments

Loss of control

Perceived loss of control at T1 was assessed using the Loss of Control (LOC) module included in the Parental Psychosocial Distress-Cancer (PPD-C) questionnaire. The PPD-C is an extensive self-report questionnaire addressing illness-specific as well as generic psychological distress in parents of children with cancer, developed by van Dongen-Melman *et al.* [20,21]. The conceptual framework of the assessment model is based on theoretical modelling, the literature, and in-depth interviews with parents of childhood cancer patients. A detailed account of the development of the entire questionnaire and the conceptual model behind it have been presented elsewhere [20,22]. The 10 items of the LOC subscale pertain to 10 different domains, where loss of control is perceived as a consequence of the child's illness; for example, 'Because of my child's

illness, I find it more difficult to have contact with friends, acquaintances, and relatives'. Items typically concern tangible aspects of experienced everyday control within several domains including social and familial relationships, own emotional and psychological experiences, financial concerns, and daily routines. The domains are listed in Table 1. At each item, the parent answers by responding with 'no' (no LOC) or 'yes' (LOC confirmed). Each participant was assigned a mean loss of control measure, ranging from 1.0 to 2.0, through dividing the total individual score by the number of completed (answered) items. A higher value for the LOC score thus reflected higher level of loss of control. In the present sample, a Cronbach's α of 0.80 indicated satisfactory internal consistency.

Posttraumatic stress

At T2, the Impact of Event Scale revised version (IES-R) was used for assessing posttraumatic stress [23]. The IES-R subscales cover three symptom domains: intrusion (8 items), avoidance (8 items), and hyperarousal (6 items), congruent with the B, C, and D symptom categories of the diagnostic criteria of posttraumatic stress disorder (PTSD; Ref. [5]). The instrument measures the extent to which respondents have experienced symptoms during the last 7 days. The five response alternatives 'Not at all', 'A little', 'Moderately', 'Quite a bit', and 'Extremely' are scored 0 to 4. Individual outcomes are expressed as sum scores, with higher scores indicating the presence of more symptoms. Possible scores were 0–32 (intrusion), 0–32 (avoidance), 0–24 (hyperarousal), and 0–88 (PTSS total). In the present study, parents were asked to complete the questionnaire with reference to the child's cancer. Cronbach's α coefficients indicated satisfactory to good internal consistency: intrusion, 0.88; avoidance, 0.87; hyperarousal, 0.82; and PTSS total, 0.93.

Data management and analysis

To investigate whether and how loss of control in those specific domains were uniquely related to PTSS at

follow-up, point biserial correlations (r_{pb}) were calculated for the associations between separate dichotomous loss of control items (i.e. domains covered in the loss of control questionnaire), on one hand, and PTS symptom dimensions and PTS total score on the other hand. To control for the influence of variation in length of time between T1 and T2 among participants, these calculations were done using a partial correlation model adjusting for length of time between assessments.

To test our hypothesis and examine whether loss of control predicted posttraumatic stress, we used linear regression analysis, inserting loss of control mean score as the independent variable and symptom categories of PTSS (intrusion, avoidance, hyperarousal) and PTSS total score in separate analyses as dependent outcome variables. Separate analyses were conducted for mothers and fathers.

In addition, the entire sample was analysed. In analyses of the entire parent group, a covariate variable was inserted, denoting whether the responder was part of a responding parent couple (parent in a couple where both parents had completed their questionnaires and thus provided data) or a singly responding parent (responder in family where the other parent had not responded). This was done to adjust for potential effect of the dependency between data provided by parents of the same child.

Results

Descriptive statistics

Most of the questionnaires came from the mother and father of a family ($n=46$, 74%), whereas 16 (26%) came from only one parent of a family.

Loss of control

Loss of control was assessed within the first 8 months of the child's treatment. The total scale scores ranged between the scale end points (1–2) with a group mean of 1.55 and an *SD* of 0.28. More than half of the parents, 55% ($n=34$), reported a sense of loss of control for the majority of the domains covered by the scale.

Table 1. Parental early loss of control (LOC) in addressed domains

Item	Domain, corresponding to items	All		Mothers		Fathers		
		N ^a	Group mean (SD)	Reported LOC ^b (%)	n ^c	Reported LOC ^b (%)	n ^c	Reported LOC ^b (%)
01	Personal social contacts ^d	61	1.41 (0.50)	40	16	44	9	35
02	Prying/disturbing thoughts	62	1.5 (0.50)	50	18	50	13	50
03	Control of the family	62	1.32 (0.47)	32	13	36	7	27
04	Personal emotions	62	1.71 (0.46)	71	19	69	25	73
05	Contact with partner	61	1.31 (0.47)	31	12	33	7	27
06	Financial concerns	62	1.73 (0.45)	73	25	69	20	77
07	Sense of identity	61	1.69 (0.47)	68	24	67	18	69
08	Sense of autonomy	62	1.61 (0.50)	61	23	64	15	58
09	Intra-familial relationships	62	1.44 (0.50)	44	16	44	11	42
10	Daily routines	62	1.79 (0.41)	79	28	78	21	81

^aEntire parent group.

^bProportions of parents who reported loss of control above the scale midpoint (1.5).

^cNumber of mothers or fathers who reported loss of control above the scale midpoint.

^dFor wording of the single items representing the domains, see Table 2.

Ten per cent ($n=6$) reported loss of control for all domains, and 5% ($n=3$) reported no loss of control in any of the domains assessed by the scale. Loss of control was most strongly experienced regarding difficulties in getting back to daily (pre-illness) routines, financial concerns, personal emotions, and sense of identity, whereas sense of having control over the family and the relationship to the partner were domains that were least subject to loss of control (Table 1). No difference was found between mothers' and fathers' total scores on the loss of control scale (t -test) or their responses regarding the separate domains of loss of control (Fisher's exact test).

Posttraumatic stress

In the T2 assessment after completion of cancer treatment, PTSS were reported by a substantial majority of the parents, where 55 of the 62 parents reported at least one symptom of PTS. PTSS total scores ranged from 0 to 61; intrusion, 0 to 24; avoidance, 0 to 22; and hyperarousal, 0 to 17. Mean/ SD of PTSS total score was 17.8/13.8, and the corresponding values for the subscales were 9.1/6.4 (intrusion), 4.6/5.3 (avoidance), and 4.1/4.2 (hyperarousal). Mothers and fathers reported similar levels of PTSS, intrusion, avoidance, and hyperarousal (t -test).

Loss of control as predictor of posttraumatic stress symptoms

Correlational analyses (partial correlation, adjusted for differences in the length of time between T1 and T2) addressing the association between domains of loss of control (assessed by single items) showed that poor control among mothers was most markedly associated with later PTSS, with significant associations between PTSS total score and loss of control regarding personal feelings, relationship with partner, relationships within the family, and difficulty in returning to daily routines (Table 2). Symptoms of hyperarousal among mothers were associated with 7 of the 10 items of loss

of control, whereas intrusion was associated with two items, and avoidance with only one item.

Among fathers, a statistically significant correlation was found only for loss of control in relation to daily routines and subsequent intrusion symptoms (Table 2). The value of the correlation coefficients occasionally paralleled that of mothers, but did not reach statistical significance.

Subsequent regression analyses confirmed that for mothers, a stronger experience of loss of control at T1 predicted higher levels of intrusion, hyperarousal, and total PTSS at T2 (Table 3). For fathers, no such associations were found. In a model covering mothers and fathers together and adjusted for potential dependency between couples (occurring when two parents of a child provided data), a similar effect of loss of control on PTS was seen as for mothers. Here, in the entire group, however, the indicated influence of loss of control on *intrusion* symptoms was reduced to below statistical significance (Table 3).

Discussion

In this study, parents' early experience of loss of control was found to predict PTSS after their children's cancer treatment. However, this effect was found only among mothers. For fathers, a relationship between loss of control and PTSS was indicated, although statistically significant for only one single domain of loss of control and the intrusion symptoms cluster of PTS.

Psychological strain and distress are typically expected to be higher among the mothers of ill children than among the fathers in terms of state anxiety [24]. However, gender differences have rarely been found for other aspects of distress [7,25]). Indeed, fathers who identify themselves as the primary medical caregivers have reported even higher levels of depression compared with mothers [26]. In the present study, mothers and fathers reported similar levels of both loss of control and PTSS. Thus, the gender effect on the association between loss of control and PTSS can hardly be explained by difference in distress between the groups.

Table 2. Associations (point biserial correlation coefficients, r_{pb}) between domains related to early loss of control at T1 and PTSS at follow-up (T2) among mothers ($n=36$) and fathers ($n=26$)

Item #	Statement (domain of loss of control)	Intrusion		Avoidance		Hyperarousal		PTS total score	
		Mothers	Fathers	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
01	It is more difficult to keep in touch with friends, acquaintances, and relatives.	-0.019 ^a	-0.020	0.302	0.110	0.165	-0.126	0.164	-0.007
02	More things easily annoy or bother me.	0.055	-0.273	-0.088	-0.203	0.374*	-0.151	0.108	-0.244
03	I feel as if I have less control of my family.	0.323	-0.081	0.358*	-0.022	0.457**	-0.115	0.431**	-0.079
04	I have poorer control over my feelings.	0.389*	0.192	0.094	0.310	0.381*	0.253	0.331	0.274
05	I have less contact with my partner.	0.319	0.214	0.206	0.136	0.483**	0.232	0.377*	0.213
06	My economy has gone downhill.	0.153	0.055	0.244	0.252	0.138	0.102	0.208	0.145
07	I am not yet my old self.	0.010	0.341	-0.141	0.363	0.048	0.344	-0.037	0.389
08	I have become more dependent on others.	0.254	0.066	0.167	-0.105	0.357*	-0.091	0.292	-0.033
09	The relations in the family are more easily disturbed.	0.435**	0.193	0.167	-0.096	0.498**	0.065	0.417*	0.074
10	I still find it difficult to pick up the routine of everyday life.	0.297	0.408*	0.201	0.254	0.405*	0.152	0.340*	0.370

^aPartial coefficients adjusted for the effect of variation between time points T1 and T2.

**Significant at the 0.01 level (two-tailed).

*Significant at the 0.05 level (two-tailed).

Table 3. Relationships between early parental loss of control (LOC) and later posttraumatic stress symptoms in parents of childhood cancer patients

	Mothers				Fathers				All parents ^a			
	N	R ²	β	F	N	R ²	β	F	N	R ²	β	F
Intrusion	36	0.188	0.434	7.88**	26	0.022	0.149	0.54	61	0.095	0.308	3.08
Avoidance	36	0.055	0.235	1.99	26	0.018	0.134	0.44	61	0.042	0.186	1.29
Hyperarousal	36	0.354	0.595	18.63***	26	0.014	0.117	0.34	61	0.178	0.385	6.37**
Total PTS score	36	0.229	0.479	10.12**	26	0.023	0.151	0.56	61	0.117	0.331	3.92*

A univariate linear regression model was used in the analysis.

^aAdjusted for potential dependency between couples (occurring when two parents of a child provided data).

*Significant at the 0.05 level (two-tailed).

**Significant at the 0.01 level.

***Significant at the 0.001 level.

The limited group size can conceivably have resulted in reduced power to detect a similar predictive significance of loss of control for later PTSS among fathers as found for mothers in this study. Inspection of outcomes of analyses shows, however, a pattern of very low regression coefficients for fathers, indicating no predictive value of loss of control for later PTSS.

As an alternative explanation, we may tentatively suggest gender differences in parenting a seriously ill child. Generally, parenting is an area particularly conditioned by gender roles, and these roles seem to become even more accentuated when a child is threatened by serious illness [27]. When a child is diagnosed with cancer, a transition of the parental roles has been found to occur [27]. One important aspect of this transition is the shift from being in control of care and decisions about one's child to experiencing others taking over. This has been found to be a source of distress for the parents [28]. We know that the threat to normal functioning may result in psychological distress [29]. Since the parent role might be more central to the identity of mothers than of fathers, the aforementioned shift to being less in control of care may particularly affect mothers, who have been found to often experience that they carry the major burden of care and responsibility following a child's severe or chronic illness [30]. In summary, our findings may reflect a kind of challenge to the parent role that tends to be of particular importance for mothers' long term psychological well-being.

When looking at the separate items of the questionnaire, the pattern was similar for mothers and fathers. The domains most frequently reported as subject to loss of control included financial concerns and daily routines. It has previously been emphasized that parents of children with cancer would benefit from practical support and assistance with household responsibilities [4]. Such support may perhaps help parents feel in control of the practical aspects of daily life.

Social contacts and relationships inside and outside the family seemed to be less affected by feelings of loss of control. Indeed, the experience of a child's cancer has sometimes been reported by parents as having positive consequences regarding marital adjustment [14]. Moreover, family cohesion is an important resource for mothers and fathers struggling with the threats of a child's cancer [12]. This was underscored by our finding

that loss of control regarding the relationships within the family, although experienced by a minority of the parents, predicted later PTSS.

There are limitations in our study that need to be considered. These partly concern the fact that we used self-report measures only, making the assessment vulnerable to the general bias that applies to self-reported data. Other issues concern the rather limited sample size. The relatively small number of fathers complicated comparisons between mothers and fathers. Finally, regarding the time points for assessment, there were discrepancies in the length of time from diagnosis to T1 and from T1 to T2. Because both loss of control and PTSS can be expected to vary over time according to a number of variables, more homogeneous assessment periods might have enhanced reliability and specificity, and a larger study group would have allowed the analysis of sociodemographic, cancer-related, and other background variables.

Forthcoming studies could benefit from the use of more complex assessments of loss of control, with multiple instruments looking at additional domains of control. Larger samples would allow the study of further risk factors, particularly whether disease-related factors such as intensity or length of treatment influence the association between loss of control and later posttraumatic stress.

In conclusion, the findings indicate that a feeling of loss of control during a child's intense cancer treatment is a salient risk factor for PTSS in mothers, but not so for fathers. The situational threat to the regular parental role, which is different for fathers and mothers, appears as a possible explanatory factor. Thus, compensating interventions should include professional support to preserve sense of control at an early stage after the child's cancer diagnosis in order to reduce the risk of posttraumatic stress.

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