



## Early avoidance of disease- and treatment-related distress predicts post-traumatic stress in parents of children with cancer

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### A B S T R A C T

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*Purpose of the research:* It has previously been demonstrated that parents of children with cancer often exhibit symptoms of post-traumatic stress (PTSS) even though the child's treatment is successfully completed. For the development of interventions we need to identify predictors of PTSS, which are possible to influence. Based on contemporary learning theory, it was hypothesized that early avoidance of disease- and treatment-related distress would predict the development of parental post-traumatic stress after completion of the child's cancer treatment.

*Methods and sample:* Parents' cognitive and behavioural avoidance of disease- and treatment-related distressing stimuli during and immediately after a child's cancer treatment and PTSS one year after the end of treatment was investigated. Data was collected with the PTSD Checklist Civilian Version (PCL-C) from 111 mothers and 109 fathers.

*Key results:* As hypothesized, avoidance during (T1–T3) and immediately after (T4) the child's treatment predicted PTSS among parents one year after (T6) completion of the child's treatment. Moreover, avoidance early on during the child's treatment seemed to be a greater risk factor for PTSS and post-traumatic stress disorder (PTSD) for bereaved than non-bereaved parents.

*Conclusions:* Avoiding reminders of stressful experiences related to a child's cancer disease during and immediately after the child's treatment seems to increase the risk for parents, mothers and fathers alike, of experiencing symptoms of post-traumatic stress later. Interventions based on cognitive behavioural therapy with elimination of avoidance as a central component may be of use in this population.

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### Introduction

For parents, the diagnosis of cancer in a child is a psychological and existential challenge. In the fourth edition of The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994) learning that one's child has a life-threatening disease is recognized as a traumatic stressor with the potential of causing post-traumatic stress disorder (PTSD). For the past decade, there has been a marked interest in investigating the potential occurrence of PTSD (Kazak et al., 2004; Pöder et al., 2008) and post-traumatic stress symptoms (PTSS) (Stuber et al., 1998) among parents of children with cancer.

The responses to a psychological trauma may involve intrusive thoughts and images of the event, avoidance of trauma-related

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stimuli triggering emotions, numbing of general responsiveness, anxiety and heightened arousal (Rothbaum and Davis, 2003). These reactions most often decrease in the days and weeks after the trauma, and finally extinguish. In terms of learning theory, the cognitive representation of a traumatic experience is integrated into the autobiographical memory base and consequently perceived as history. However, in unfavourable cases this integration fails. According to Ehlers and Clark (2000) PTSD is caused by a dysfunction relating to the episodic memory, which hinders the elaboration of a traumatic experience and is putting it into a meaningful context within a person's cognitive schema. A vicious circle is formed when the person starts to avoid reminders of the trauma in order to escape intrusions, which in turn impedes the reorganisation of trauma memory. Studies have shown that the degree of disorganised trauma memory predicts later PTSD (Halligan et al., 2003; Murray et al., 2002) and is related to the development of PTSD (Murray et al., 2002) supporting Ehlers and Clark's model. One of the cognitive processes in this model is avoidance.

Avoidance occupies a particular position among the symptoms of post-traumatic stress. Intrusions and arousal are considered

involuntary responses, while avoidance is considered an intentional strategy (Plumb et al., 2004). According to contemporary learning theory, avoidance prevents the elaboration of a trauma and thus the extinction of the emotional responses (Whealin et al., 2008). It has been shown that avoidance is associated with an elevated level of psychological distress among parents of children with cancer (DuHamel et al., 2004; Lindahl Norberg et al., 2005a) and in other traumatized populations (Littleton et al., 2007). In order to develop an understanding of parents' emotional reactions when a child is diagnosed with cancer, we examined parents' cognitive and behavioural avoidance of disease- and treatment-related stimuli during and immediately after a child's cancer treatment and PTSD as well as PTSS one year after the end of treatment. It was hypothesized that avoidance during the child's treatment predicts PTSD and PTSS among parents of children with cancer.

## Method

The results are based on data collected within the ongoing project: Occurrence and development of post-traumatic stress disorder among parents of children with cancer (first report Pöder et al., 2008). The project has a longitudinal design with seven assessments (T1–T7). The first three (T1–T3) are related to the time of the child's diagnosis, whereas the following are related to the end of treatment (T4–T7)/the child's death (T5–T7). Data collected at T1–T4 and T6 are presented in the present paper: T1 = one week, T2 = two months, and T3 = four months after the diagnosis. T4 = one week after the end of treatment/six months after bone marrow, stem cell or organ transplantation, and T6 = one year after the end of treatment/eighteen months after transplantation/one year after the child's death.

## Sample

Parents of children treated for cancer at four of the six Swedish paediatric oncology centres, Gothenburg, Linköping, Umeå, and Uppsala, were consecutively included during 2002–2004, over eighteen months at each centre. The inclusion criteria were Swedish and/or English speaking parents (including stepparents) of children, 0–18 years, diagnosed with cancer for the first time and scheduled for chemo- and/or radiotherapy.

Three hundred and twenty five parents were invited to participate, of whom 66 refused participation – yielding a response rate of 80%. In the subsequent assessments parents were approached if the child was on curative treatment (T2, T3), had ended a favourable treatment (T4), and had ended a favourable treatment or had passed away (T6).

The present study includes all the parents who participated at T6. Among those, all participated at T1, 216 at T2 (3 were temporarily excluded, 1 refused participation), 190 at T3 (29 were temporarily excluded, 1 temporarily refused participation), and 198 at T4 (19 were temporarily excluded, 3 temporarily refused participation). One hundred and seventy three parents participated at T1–T4 and T6.

For a presentation of parent and child characteristics, see Table 1. Fathers were older than mothers ( $M = 40.0$  years,  $SD 6.7$  vs.  $M = 37.2$  years,  $SD 6.3$ ). More fathers than mothers worked full time before the child's diagnosis (68% vs. 32%). The families lived an average of 146 km from the respective centre ( $SD 114$ , range 1–600 km).

## Assessments

Data on PTSS and PTSD was collected with the PTSD Checklist Civilian Version (PCL-C) (Weathers et al., 1993) through structured

**Table 1**  
Parent ( $N = 220$ ) and child characteristics at T1.

|                                                   | %     | <i>n</i>  |
|---------------------------------------------------|-------|-----------|
| Mothers/fathers                                   | 50/50 | (111/109) |
| Age of parent, year                               |       |           |
| <30                                               | 10    | (21)      |
| 30–39                                             | 52    | (114)     |
| ≥40                                               | 38    | (85)      |
| Place of origin                                   |       |           |
| Nordic country                                    | 96    | (210)     |
| Education                                         |       |           |
| ≤Nine year                                        | 14    | (30)      |
| Upper secondary                                   | 52    | (114)     |
| University                                        | 34    | (76)      |
| Work status                                       |       |           |
| Full time or student (full time)                  | 64    | (142)     |
| Part time                                         | 21    | (46)      |
| Not working                                       | 15    | (32)      |
| Household income per year, €                      |       |           |
| ≤32,200                                           | 16    | (35)      |
| 32,300–53,700                                     | 55    | (122)     |
| ≥53,800                                           | 26    | (57)      |
| No answer/don't know                              | 3     | (6)       |
| Parent of daughter/son with cancer                | 47/53 | (86/98)   |
| Age of child with cancer, years                   |       |           |
| 0–3                                               | 23    | (51)      |
| 4–7                                               | 31    | (68)      |
| 8–12                                              | 26    | (57)      |
| 13–18                                             | 20    | (44)      |
| Sibling/s, yes                                    | 92    | (203)     |
| Diagnosis                                         |       |           |
| Leukaemia                                         | 39    | (86)      |
| Lymphoma                                          | 19    | (41)      |
| CNS tumour                                        | 12    | (26)      |
| Other solid tumour                                | 30    | (67)      |
| Treatment modalities                              |       |           |
| Chemotherapy                                      | 35    | (76)      |
| Chemotherapy in combination with other treatments | 51    | (112)     |
| Treatment including transplantation               | 14    | (32)      |

telephone interviews. The PCL-C consists of 17 items organized in three subscales. Eight items (Items 1–8) are keyed to a specific trauma, in this study to the child's cancer disease. The respondent is asked to report how much he or she has been bothered by each item during the last month (at T1 during the last week) on a five point scale ranging from not at all (1) to extremely (5). The subscales correspond to the three symptom clusters of PTSD according to the DSM-IV (American Psychiatric Association, 1994): re-experience (5 items; Cronbach's alpha in this sample at T6: 0.88), avoidance (7; alpha 0.82), and hyperarousal (5; alpha 0.89). The total score ranges from 17 to 85 (alpha 0.94). The PCL-C symptom criteria method (Weathers et al., 1993), i.e. a score of  $\geq 3$  on at least one symptom of re-experience, three symptoms of avoidance, and two symptoms of hyperarousal was used to identify parents scoring as potential cases of PTSD. This method has shown diagnostic effectiveness for PTSD when compared to the Structured Clinical Interview for DSM-IV, PTSD module among mothers of childhood cancer survivors (Manne et al., 1998).

Two items in the PCL-C address cognitive and behavioural avoidance, respectively. One item concerns avoidance of thoughts/talks/feelings related to the child's cancer disease, whereas one item concerns avoidance of activities/situations that may remind them of the child's cancer disease. These items were used to assess avoidance in the present study.

## Procedure

Ethical approval was obtained from the local ethics committees at the respective faculties of medicine. Parents who met the inclusion criteria received written and oral information about the

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