

# **The Impact of Parental Stress on the Behaviour of a Burn Injured Child, 0 – 3 months after a Burn Event**

Masterthesis

R. Boot (0301787)

Department of Clinical and Health Psychology

Utrecht University

July 2009

Supervision by:

M.J.M. van Son, PhD.

Utrecht University

A. Bakker, MA.

Association of Dutch Burn Centres

N. van Loey, PhD.

Association of Dutch Burn Centres



## Index

Preface	3
Abstract	4
Introduction	5
Methods	
<i>Design and procedure</i>	9
<i>Participants</i>	12
<i>Measures</i>	12
<i>Data analysis</i>	14
<i>Operationalized hypotheses</i>	15
Results	
<i>Prevalence of behavioural problems in children with burns</i>	16
<i>Differences between fathers and mothers</i>	16
<i>Parental stress related to children's characteristics and behavioural problems</i>	17
<i>Feelings of guilt and parental stress</i>	18
<i>Path analyses: parental stress as a moderator between the hypothesized variables and behavioural problems</i>	19
Discussion	20
References	23
Appendix	
1. <i>Information letter for parents of children with burns (Dutch)</i>	28
2. <i>Informed consent form for both parents/guardians (Dutch)</i>	31
3. <i>Child Behaviour Checklist (CBCL) for 1.5/5 years (Dutch)</i>	33
4. <i>Impact of Event Scale (Dutch)</i>	36
5. <i>Schematic view of the questionnaires at different measurements</i>	38

## **Preface**

After 3 months, about 45 days of travelling between Utrecht and Beverwijk, days of working at home, a lot of chocolate Easter eggs, liquorice, other candy and heaps of spring-feelings-tea, I've finished my graduation thesis and I'm really satisfied with the result. It is a special and exciting feeling to hand in my thesis and to know that it is the end of 6 fantastic years as a student, but also the beginning of a new period.

First, I would like to thank Maarten van Son. Thank you for finding me this research place and for your inspiring and critical notes and sharp remarks. I enjoyed working with you, when I was a student as well as when I was your colleague.

I also would like to thank Anne Bakker, my supervisor of the Association of Dutch Burn Centres in Beverwijk. Thank you for all the helpful tips, inspiration and critical notes. It was really nice that I never had to hesitate to ask you any questions. I enjoyed working with you and wish you all the best with your PhD. research. My thanks go to Nancy van Loey as well, who supervised me when Anne was on holiday. Thank you for helping me in the final weeks of my thesis.

Last, I would like to thank my family and friends, for the useful tips and for always supporting me.

I hope you enjoy reading my thesis.

Renske Boot

July 2009

## **Abstract**

**Objective** This study examines the prevalence of problem behaviour in burn injured children who are 0 – 4 years old. Furthermore, it explores the role of TBSA, gender and age of the child and feelings of guilt of the parents on parental stress symptoms and investigates if there are differences between fathers and mothers in reporting problem behaviour, parental stress and feelings of guilt. **Method** Parental stress symptoms were measured with the Impact of Event Scale in a prospective cohort study with a follow up at 3 months. Problem behaviour in children was measured using the Child Behaviour Checklist (CBCL) for 1.5/5 years. **Results** Complete data sets were available from 39 children. Mothers have higher self-reported posttraumatic stress and feelings of guilt and reported more problem behaviour of their child than fathers do. Multiple regression analyses showed no statistically significant effect of TBSA, gender and age of the child on parental stress on 1 and 3 months post-burn. A path analysis of the model of fathers, where stress 3 months post-burn and PTSD in the burn injured children were being used, provides a reasonably well-fitting representation of the data. **Conclusions** Problem behaviour in children with burns was not more prevalent in this study than it is in the general Dutch population. Remarkable results were observed in fathers. The bigger the burn, the more feelings of guilt a father experienced and the guiltier a father felt, the more PTSD symptoms their child displayed. In mothers, TBSA did not have a relationship with feelings of guilt and the CBCL.

**Keywords** burn injured child, parental stress, problem behaviour, parental guilt

## **Introduction**

Half of the hospital admissions in burn centres involves children; two thirds of them are between 0 – 4 years (ADBC). Although most children with burn injuries do well after the first year (Meyer et al., 1994), an important number of burn injured children and their parents can experience severe difficulties, both physically and psychologically (Caffo & Belaise, 2003; Gorga et al., 1999).

Yule (2001) concluded that among young children who experienced such a major event, a broad range of mood and anxiety as well as behavioural problems may be observed. A burn injury is an acute event, with long-term consequences for the child and its parents and is therefore a risk for psychopathology. Posttraumatic stress disorder (PTSD) has been the most clearly established variant of psychopathology in children with burns (Stoddard & Saxe, 2001). PTSD is characterized by re-experiences of the traumatic event, avoidance of stimuli associated with the trauma and numbing of general responsiveness, and increased arousal. In children this may manifest itself by disorderly or agitated behaviour (APA, 2000).

Research suggests several risk factors in children for developing stress related symptoms and disorders after a traumatic event experienced by a child. Young age, temperament and female gender (Ackerman, Newton, McPherson, Jones, & Dykman, 1998; Green et al., 1991; Wright & Fulwiler, 1974) are described risk factors of children's PTSD, and on top of those factors, parental factors have an important role in the development of children's PTSD (Hall et al., 2006). Several studies (Shemesh et al., 2005; Yehuda, Halligan, & Bierer, 2002; Yehuda, Halligan, & Grossman, 2001) suggested that a traumatic event experienced by the parent can lead to emotional trauma symptoms in their children. Concluding, in which way children react to their diagnosis and treatment may be related to parents' psychological symptoms (Roddenberry & Renk, 2008).

As mentioned above, a traumatic event experienced by a child has impact on its parents as well. Research in various other pediatric populations show that parents often

react with grief, anger and shock to the diagnosis and treatment of their children (Balluffi et al., 2004; Kazak et al., 2006) and may develop their own PTSD symptoms.

Rizzone et al. (1994) for instance concluded that just after the burn event 52% of the mothers met the criteria for PTSD. More than 7 years post-burn still 16% of the sample was diagnosed with PTSD. Hall et al. (2006) demonstrated a model of the risk factors for PTSD symptoms in parents of burn injured children. They showed that about 47% of the parents reported significant posttraumatic stress symptoms 3 months post-burn. An earlier study reported that mothers of preschool children with burns showed higher anxiety levels compared to mothers of children with other injuries or illnesses (Kent, King, & Cochrane, 2000).

Besides PTSD, parental feelings of guilt appear to be a consequence of their child's burn injury (Cella, Perry, Kulchycky, & Goodwin, 1988). Lee et al. (2001) defined guilt as 'a self-conscious affect that relates to a sense of responsibility and the cause of harm to others'. In two studies, over 70% of the mothers had the feeling that they were directly responsible for the burn event and felt guilty (El Hamaoui, Yaalaoui, Chihabeddine, Boukind, & Moussaoui, 2006; Mason, 1993). Bakker, Van Loey, Van Son, & Van der Heijden (submitted) demonstrated that the interaction between feelings of guilt and burn severity significantly influences the course of PTSD symptoms. Over a period of 10 years, mothers who felt guilty about the event and who had a child with more extensive scarring, had higher PTSD scores. Woodward (1959) suggested that guilt, studied in mothers, can be increased by anxiety. In contrast it was identified that guilt is a major cause of anxiety for mothers (Denayer, Evers-Kiebooms, & Van den Berghe, 1990). Liber et al. (2006) stated that involvement of parents in the accident, unintentionally or by absence, may influence parental stress, in terms of feeling guilty about the accident. So, research proposed that guilt can influence the extent of anxiety experienced by a parent (Denayer et al., 1990), but anxiety can also intensify feelings of guilt (Woodward, 1959).

Several factors can predict PTSD in parents of burn injured children. The percentage of Total Body Surface Area (TBSA) of the burn is concluded to be a strong

predictor for PTSD symptoms in parents (Rizzone et al., 1994), but this is conflicting with previous findings that TBSA was a poor predictor of parents' stress symptoms (Cella et al., 1988). Hall et al. (2006) indicated a model that indicated three ways that influenced posttraumatic stress symptoms in parents. A conflict with their children during hospitalisation, parents' dissociation and children's PTSD were significantly associated with PTSD symptoms in parents. The gender of the parent can be a risk factor for PTSD in parents, but to our knowledge, there is scarce literature about this matter. In most studies, only mothers were asked to participate (Bakker et al., submitted; Fukunishi, 1998), fathers did not had a high response rate (Hall et al., 2006; LeDoux, Meyer, Blakeney, & Herndon, 1998).

Parent's and children's PTSD are thought to influence each other, which is also suggested in other pediatric injury literature. Nugent, Ostrowski, Christopher, & Delahanty (2007) suggested, in a sample of 82 children, that parental PTSD has a major impact on the development of children's PTSD. They suggested that parental PTSD at 6 weeks predicted 6-month child PTSD after controlling for demographics and general parent distress. By contrast, general distress reported by parents did not predict subsequent child PTSD after controlling for 6-week parent PTSD, suggesting that specific parental PTSD may be of greater importance than general levels of distress in contributing to child maladaptation following trauma. DeVries et al. (1999) showed that children's PTSD was explained by parent PTSD as well as parent PTSD was explained by children's PTSD.

There is scarce literature regarding the question whether behavioural problems (e.g. aggressive, more reserved or more anxious) in children with burns occur more often than in normal children. Koot & Verhulst (1991) show that the prevalence of behavioural problems in the general Dutch population is 7,8%; the prevalence of internalising problematic behaviour in the general population is 4-7%. Koot & Verhulst (1991) also found that the mean total problems score of the CBCL is 33.4 (SD = 16.8), the mean internalising problems score is 4.4 (SD = 4.0) and the mean externalising problems score is 17.0 (SD = 9.2).

Research that focuses on PTSD in young children with burns and their parents is scarce as well, because the DSM-IV criteria for PTSD are not useful for very young children, as shown in a pilot study (Scheeringa, Zeanah, Drell, & Larrieu, 1995). The relevant studies often concern the impact on either the parents or the children and not the reciprocal impact on both of them and in most cases it regards older children. The reciprocal impact on both the parents and the children is an interesting hypothesis, because young children rely heavily on their parents and any effect on adults can have a major impact on children (Pine & Cohen, 2002; Stoddard et al., 2006). Although Hall et al. (2006) concluded that parents' PTSD was influenced by children's PTSD, there is little literature that investigated the hypothesis whether stress reactions or PTSD in parents influences the child's psychological distress or his/her behaviour.

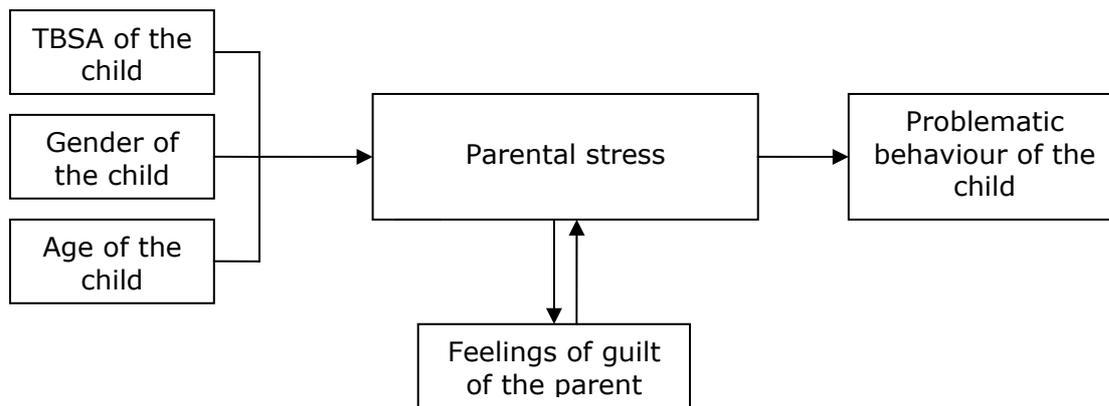
The aim of this study is to examine the prevalence of behavioural problems and the impact of parental stress reactions subsequent to a burn event of the child on the problematic behaviour of the burn injured child. Furthermore, this study examines the role of child's TBSA, child's age, child's gender and parental feelings of guilt on parental stress and differences between fathers and mothers in reporting problem behaviour, parental stress and feelings of guilt.

Therefore, the hypotheses of this study are:

1. The prevalence of behavioural problems in children with burns between 0 – 4 years of age is higher than in the general Dutch population.
2. Fathers and mothers differ in reporting behavioural problems of their child, the extent of posttraumatic stress and feelings of guilt.
3. Parental stress is related to TBSA, age and gender of the child.
4. Parental stress predicts problematic behaviour in children with burns.
5. Feelings of guilt of the parents and parental stress are related.
6. Parental stress is a moderator between children's characteristics, feelings of guilt and problem behaviour in children with burns.

A schematic view of the hypotheses is shown in Figure 1.

**Figure 1.** Schematic view of the hypotheses



## Methods

### *Design and procedure*

This study is part of a larger prospective cohort study with a follow-up at 3 months in children with burns and was conducted in three Dutch and four Belgian burn centres between October 2007 and February 2009. The study focuses on children with burns between 8 months and 4 years old.

When a child was hospitalised in one of the seven participating burn centres, their parents were invited to participate in this study by a local researcher, i.e. nurse or psychologist. Children were included in this study if a) they were between 8 months and 4 years old, b) the minimal length of stay was 24 hours, c) skin burns had a minimal Total Body Surface Area (TBSA) of 1%.

A child was excluded from the study if a) he/she was deceased, b) there was inhalation injury only, c) the child was mentally retarded, d) the parents had an insufficient proficiency of the Dutch language. As seen in Figure 2, 333 children were admitted in one of the participating burn centres between October 2007 and February 2009. Two-hundred-two children met one or more of the exclusion criteria and were excluded from the study; therefore 131 children were eligible. Parents of 21 children declined the invitation, 13 children were missed, i.e. because of absence of the investigator, 2 children lived abroad. Nine children were not invited because the investigator estimated that completing the questionnaires was too much of a burden for

the parents and 4 children could not participate due to other reasons. Of the 131 children and parents who were eligible, parents of 82 children were enrolled in study; therefore the study has a response rate of 62.6%.

For the purpose of this study 39 of the 82 enrolled children were analyzed, because their parents completed all the questionnaires until 3 months. Seven children dropped out of the study ahead of the 3 months measurement and 36 children were admitted after 7 November 2008 and had not yet completed the 3 month measurement at the end of February 2009.

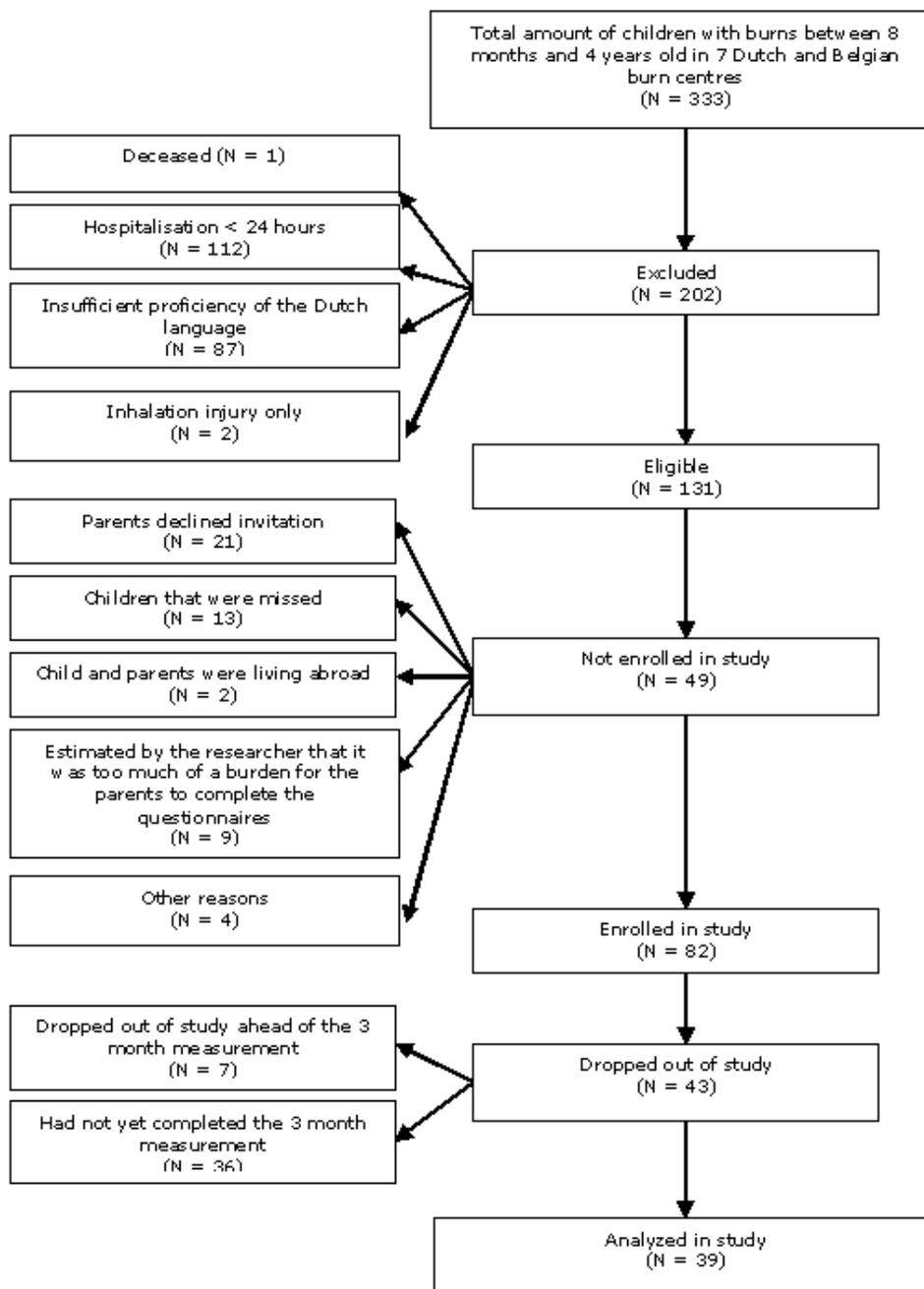
There were no differences between the eligible children, who were not enrolled in the study (Figure 2) and the eligible children who were enrolled in terms of TBSA ( $\chi^2$  (29,  $N = 131$ ) = 19.23,  $p = .83$ ), age ( $\chi^2$  (1,  $N = 131$ ) = .65,  $p = .42$ ), gender ( $\chi^2$  (1,  $N = 131$ ) = 1.55,  $p = .21$ ) and length of stay in the hospital ( $\chi^2$  (27,  $N = 131$ ) = 15.16,  $p = .97$ ). There were no differences as well between analyzed children and children who had not yet completed the questionnaires at the 3 months measurement in terms of TBSA ( $\chi^2$  (24,  $N = 82$ ) = 30.35,  $p = .17$ ), age ( $\chi^2$  (73,  $N = 82$ ) = 72.99,  $p = .48$ ), gender ( $\chi^2$  (1,  $N = 82$ ) = 1.73,  $p = .19$ ) and length of stay in the hospital ( $\chi^2$  (26,  $N = 82$ ) = 19.23,  $p = .83$ ).

The parents received patient information describing the purpose and methods of the study and were given a week to consider their participation. People who filled in the questionnaires were guaranteed that their data was processed anonymously. Informed consent forms (Appendices 1 and 2) were included in which parents were asked to give permission to participate in this study. All parents signed the informed consent forms. The parents had to fill in the first questionnaires within 30 days post-burn. When the child was discharged from the hospital, follow-up questionnaires were sent by mail, including a stamped return envelope, at 3 months post-burn. Appendix 5 shows a schematic view of the different measurements.

The study in the three Dutch burn centres was nationally approved by the Independent Ethics Committee of the foundation 'Evaluation of Ethics in Biomedical Research' Assen, the Netherlands and after that the study was approved per burn

centre. In Belgium the study first was approved by the Committee Medical Ethics of University Hospitals in Gent. After that, the study was approved per burn centre by the Committee of Medical Ethics in Antwerp, Committee Medical Ethics of University Hospitals in Leuven and the Committee of Medical Ethics in Brussels.

**Figure 2.** Participant flowchart



## Participants

*Characteristics of the parents.* In the analyzed cases 39 mothers and 27 fathers participated. In 27 cases both the parents participated and in 12 cases only the mother took part in the study. The parents had a mean age of 32.1 years ( $SD = 5.7$ ), ranging from 20 to 43 years old. Most of the parents were married (53.8%) or lived together (15.4%) and had a job (64.1%). The educational level ranged from special education to university, although most parents ended their schooling after high school at the age of 18 (54.0%).

*Characteristics of the child.* The analyzed children had a mean age of 1.9 years ( $SD = 0.8$ ), range of 0.9 to 4.0 years. There were 30 boys and 9 girls. TBSA ranged from 1 to 40% ( $M = 7.7$ ,  $SD = 6.1$ ). Burns were caused by hot liquids (94.8%), electricity (2.6%) and contact with a hot object (2.6%). The average length of stay in the hospital was 11.4 days ( $SD = 17.1$ ). Based on the medical file, most of the children did not have a behavioural disorder previous to the burn event (84.6%) or it was unknown if the child had a behavioural disorder (12.8%). Data of 1 child about a behavioural disorder was missing (2.6%).

## Measures

*Impact of Event Scale (IES).* The IES aims to measure the current degree of subjective impact experienced as a result of a specific event (Horowitz, Wilner, & Alvarez, 1979). The IES contains 15 questions and is measured on a 4-point Likert-scale ranging from *never* to *often* (Horowitz et al., 1979). The questionnaire consists of a total scale, which contains 2 subscales, i.e. the avoidant scale and the re-experience scale. For the purpose of this study, only the total scale is used. The total score can range between 0 and 75. A score of 26 and higher suggests that parents experience clinically significant problems in the aftermath of the accident (Brom & Kleber, 1985).

The psychometric properties of the original IES as well as the Dutch version are good (Joseph, 2000; Van der Ploeg, Mooren, Kleber, Van der Velden, & Brom, 2004).

Van der Ploeg et al. (2004) demonstrated that support was found for the construct validity and showed that the reliability was good (Cronbach's  $\alpha = .86$ ) (Van der Ploeg et al., 2004). Parents completed the IES within the first month and 3 months post-burn.

*Child Behaviour Checklist (CBCL) for 1.5/5 years.* The CBCL is a widely used questionnaire to investigate problem behaviour in children. In this study the questionnaire for children between 1.5 and 5 years old is used (Achenbach & Edelbrock, 1983). The CBCL has 2 broadband groupings, one for internalising behaviour and one for externalising behaviour. An advantage of those 2 groupings is that children may have various psychological problems following a traumatic event (Dehon & Scheeringa, 2006). For the internalising scale, a score between 14 and 17 indicates the borderline range and a score of 18 or more scores in the clinical range. For the externalising scale, a score between 21 and 24 indicates the borderline range and a score of 25 or more scores in the clinical range. The Dutch version of the CBCL is supportive of the reliability and validity of the test in total as well as on the 2 broadband groupings (Koot, Van Den Oord, Verhulst, & Boomsma, 1997).

Dehon & Scheeringa (2006) proposed that a subset of 15 items in the CBCL/1.5-5 could be used for screening posttraumatic symptomatology in young children. This modified CBCL-PTSD scale has good psychometric properties and showed a Cronbach's  $\alpha$  of .83 (Dehon & Scheeringa, 2006). The same study also showed that the CBCL-PTSD scale explained 43% of the variance in children's PTSD symptoms. Six of the items are also part of the internalising scale and 3 are part of the externalising scale. This scale seems to be a promising measurement to investigate PTSD symptoms in young children. A cut-off score of 9 is used as indicator whether or not the child meets the modified criteria for PTSD. Parents were asked to complete the CBCL 3 months post-burn.

*Feelings of guilt.* Feelings of guilt were measured within 1 month post-burn with a questionnaire that measured feelings of responsibility right after the accident. Parents had to answer the following question: 'To what extent applies the following feeling as

you think about the accident that caused the burns?’ Responses were measured on a 4-point scale ranging from *never* to *often*. Apart from guilt, the questionnaire also measured related emotions like anxiety, shame, anger, sorrow and regret (Roseman, Spindel, & Jose, 1990). The related emotions correlated with feelings of guilt in mothers as well as in fathers. Feelings of guilt in mothers correlated significantly with shame (.555\*\*), anger (.498\*\*), sorrow (.361\*) and regret (.568\*\*). Feelings of guilt in fathers correlated significantly with anxiety (.443\*), shame (.640\*\*), anger (.457\*), sorrow (.547\*\*) and regret (.715\*\*)¹.

### *Data analysis*

Only children of parents who completed all the questionnaires until February 2009 were analyzed. To assess whether children and parents who completed the questionnaires differed from children and parents who did not finish the questionnaires, they were compared with  $\chi^2$ . To investigate the predictive value of TBSA, sex of the child, age of the child and feelings of guilt of the parents on parental stress, a multiple regression analysis was used.

A path analysis was used to test the role of parental stress reactions as a moderator between the children’s characteristics and problem behaviour of children with burns and between parental feelings of guilt and problem behaviour of children with burns. The rule of thumb for sample size in path analyses is a minimum of 5 subjects per parameter in the model (indicated by a straight arrow in Figure 1) in order to have confidence in the results (Bentler & Chou, 1988). Therefore, the 6 parameters in this study indicate a minimal amount of 30 participants. With a sample size of 39 participants this criterion is met. To accomplish the path analysis, AMOS version 17.0 (SPSS Inc., Chicago, IL, USA) is used. In the analysis child’s TBSA, child’s sex and child’s age were included as predictors of parental stress reactions. It was analyzed as well if parental feelings of guilt predicted parental stress and vice versa and if parental stress predicts problem behaviour in a burn injured child. All analyses were conducted using SPSS,

---

¹ \*  $p < .05$ , \*\*  $p < .01$

version 17.0 (SPSS Inc., Chicago, IL, USA). For all statistical tests an alpha level of .05 was used.

### *Operationalised hypotheses*

The hypotheses, as proposed in the introduction, are operationalised as follows:

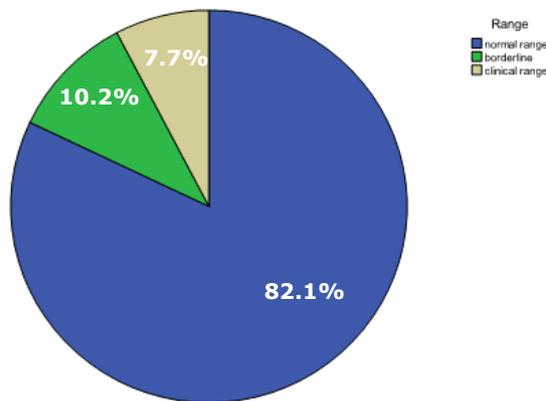
1. *The prevalence of behavioural problems in children with burns between 0 – 4 years of age is higher than in the general Dutch population.* The prevalence of behavioural problems in children with burns is more than 7.8% (Koot & Verhulst, 1991).
2. *Fathers and mothers differ in reporting behavioural problems of their child, the extent of posttraumatic stress and feelings of guilt.* There are significant differences between fathers and mothers on the CBCL scales, Impact of Event Scale and feelings of guilt questionnaire.
3. *Parental stress is related to TBSA, age and gender of the child.* Parents score higher on the IES after 1 and 3 months post-burn if TBSA is larger (Rizzone et al., 1994), if the child is younger (DeVries et al., 1999) and when the child is a girl (Green et al., 1991).
4. *Parental stress predicts problematic behaviour in children with burns.* Scores on the IES 1 and 3 months post-burn are positively related to scores on the CBCL and CBCL-PTSD scale.
5. *Feelings of guilt of the parents and parental stress are related.* The extent of subjective feelings of guilt is positively related to scores on the IES at the same time.
6. *Parental stress is a moderator between children's characteristics, feelings of guilt and problem behaviour in children with burns.* Using a path analysis, it is investigated if the suggested model fit the sample data.

## Results

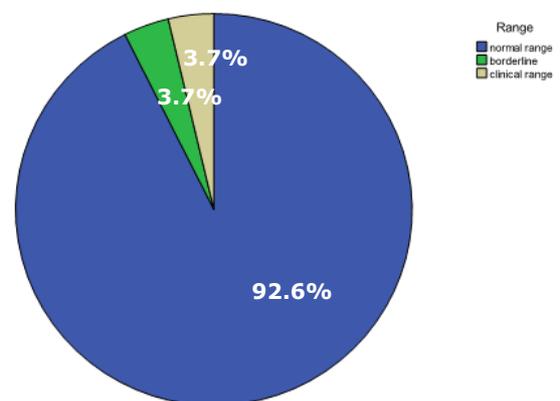
### *Prevalence of behavioural problems in children with burns*

Most mothers scored the problem behaviour of their child (CBCL-total scale) in the normal range (82.1%), whereas 10.2% scored in the borderline range and 7.7% scored in the clinical range. Most of the fathers, 92.6%, scored the problem behaviour of their child in the normal range, 3.7% in the borderline range and 3.7% in the clinical range. The percentages of the fathers differed significantly from the percentages of the mothers ( $\chi^2 (4, N = 27) = 21.240, p < .01$ ). According to the mothers, 12.8% of the burn injured children scored 9 or higher at the CBCL-PTSD scale. According to the fathers, 3.7% of the children scored 9 or higher at the CBCL-PTSD scale. The percentages of the fathers and mothers differed significantly ( $\chi^2 (1, N = 27) = 8.308, p < .01$ ).

**Figure 3.** Prevalence of behavioural problems, reported by mothers



**Figure 4.** Prevalence of behavioural problems, reported by fathers



### *Differences between fathers and mothers*

Mean scores of the mothers and the fathers on the IES and the guilt measure showed that mothers tend to report more posttraumatic stress and feelings of guilt than fathers do (Table 1). There were almost no differences observed in mothers and fathers reporting problem behaviour of the burn injured child. Except for the CBCL-scale sleep

problems ( $t(26) = 2.164, p = .04$ , two-tailed), differences in scores between the fathers and the mothers of one child were not statistically significant.

**Table 1.** Descriptives: mother's and father's scores on IES, guilt and CBCL

	Mothers		Fathers		<i>r</i>
	M (SD)	Range	M (SD)	Range	
Impact of Event Scale M1	27.32 (14.31)	3.0 - 62.0	17.50 (13.89)	0.0 - 44.0	.286
Impact of Event Scale M2	20.82 (13.50)	0.0 - 50.0	9.96 (10.30)	0.0 - 39.0	.597**
Feelings of guilt	1.79 (1.68)	1.0 - 5.0	1.52 (1.61)	1.0 - 5.0	.486*
CBCL-total	31.33 (18.89)	0.0 - 81.0	25.97 (15.11)	3.0 - 66.0	.743**
CBCL-internalising	6.93 (5.64)	0.0 - 24.0	5.08 (4.18)	0.0 - 19.0	.772**
CBCL-externalising	13.53 (8.02)	0.0 - 37.0	12.00 (7.29)	1.0 - 35.0	.751**
CBCL-PTSD	5.10 (3.28)	0.0 - 14.0	4.11 (2.74)	0.0 - 11.0	.625**

\* $p < .05$ , \*\* $p < .01$ .

Mother's:  $N = 39$ , father's:  $N = 27$

Unlike fathers, the mean stress scores of all mothers were above the clinical cut-off point of 26 at measurement 1. Paired-samples t-tests showed a statistically significant decrease in mean stress scores between measurement 1 and 2 in fathers ( $t(28) = 4.932, p < .01$ ), as well as in mothers ( $t(37) = 3.589, p < .01$ ). Nevertheless, the scores of the mothers at measurement 2 remained high. The scores on the IES of father and mothers at measurement 1, feelings of guilt and CBCL scores did not differ significantly between fathers and mothers. The scores on the IES of mothers and fathers at measurement 2 showed a significant difference ( $t(27) = 4.107, p < .01$ ).

#### *Parental stress related to children's characteristics and behavioural problems*

There were almost no relationships found between age and gender of the child and the scores on the IES, CBCL and feelings of guilt questionnaire. However, it was observed that the older the child was during the burn event, the less behavioural problems it displayed afterwards, according to the mother ( $r = -.320^*$ ). It was observed as well that a larger TBSA is positively correlated with feelings of guilt in fathers ( $r = .468^*$ )<sup>2</sup>. Tables 2 and 3 show correlations between hypothesized predictors and outcome for mothers (Table 2) and fathers (Table 3).

<sup>2</sup> \*  $p < .05$

*Feelings of guilt and parental stress*

In mothers, feelings of guilt correlated positively with the IES at measurement 1 and measurement 2. Feelings of guilt explained 34.6% of the variance in stress in mothers 1 month post-burn. In fathers, feelings of guilt only significantly correlated with IES at measurement 2 and explained 23.3% of the variance in stress 3 months post-burn.

Tables 2 and 3 also showed that feelings of guilt of fathers positively correlate with the CBCL-PTSD scale of their child. There was no significant relation between feelings of guilt of fathers and IES scores of mothers. On the other hand, there was a significant relation between feelings of guilt of mothers and IES scores of fathers with an alpha level of .01. The more guilty fathers felt about the burn event, the more stress was experienced by the mothers.

**Table 2.** Correlation matrix: Correlation of mothers' scores on IES, CBCL and guilt questionnaires (N = 39)

	2	3	4	5	6	7	8
1. TBSA	-.149	.124	.126	-.296	-.248	-.295	-.294
2. Feelings of guilt	-	.589**	.463**	.382*	.413*	.396*	.294
3. IES M1	-	-	.682**	.289	.349*	.215	.296
4. IES M2	-	-	-	.246	.327*	.113	.260
5. CBCL-total	-	-	-	-	.853**	.884**	.934**
6. CBCL- internalising	-	-	-	-	-	.583**	.788**
7. CBCL-externalising	-	-	-	-	-	-	.799**
8. CBCL-PTSD	-	-	-	-	-	-	-

\* $p < .05$ , \*\* $p < .01$ .

**Table 3.** Correlation matrix: Correlation of fathers' scores on IES, CBCL and guilt questionnaires (N = 27)

	2	3	4	5	6	7	8
1. TBSA	.468*	-.047	-.017	-.096	-.127	-.095	.092
2. Feelings of guilt	-	.334	.483*	.456*	.423*	.447*	.606**
3. IES M1	-	-	.817**	.296	.345	.146	.276
4. IES M2	-	-	-	.247	.445*	.014	.383*
5. CBCL-total	-	-	-	-	.827**	.887**	.899**
6. CBCL- internalising	-	-	-	-	-	.562**	.804**
7. CBCL-externalising	-	-	-	-	-	-	.754**
8. CBCL-PTSD	-	-	-	-	-	-	-

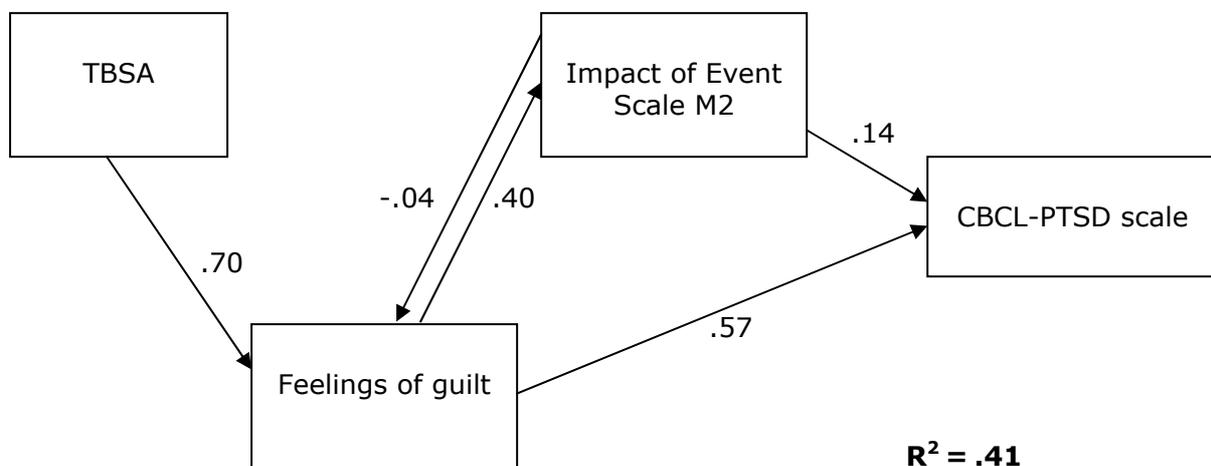
\* $p < .05$ , \*\* $p < .01$ .

*Path analyses: parental stress as a moderator between the hypothesized variables and behavioural problems*

Path analyses indicated that the model that was proposed in the introduction of this thesis did not fit the data well (comparative fit index (CFI) = .548, root mean square error of approximation (RMSEA) = .164). Although the model tended to get a better fit when the children's characteristics (TBSA, age and gender) were removed, it was still not significant. The models fitted better, but not significant, when IES measurement 2 was taken into account, instead of IES measurement 1.

However, a model with CBCL-PTSD scale and fathers stress at 3 months post-burn fitted the data reasonably well (Figure 5). The model displayed the results of the model with standardized regression coefficients (betas) given for each path. In the model, guilt is a moderator between TBSA and the CBCL-PTSD scale. The model yielded strong fit indices:  $\chi^2 (1, N = 39) = .996, p = .32, CFI = 1.000$  and  $RMSEA = 0.000$ . The results indicate two direct pathways to PTSD symptoms in children, that is parental stress at 3 months post-burn ( $\beta = .14$ ) and feelings of guilt ( $\beta = .57$ ). Feelings of guilt, in turn, were directly related to TBSA. As expected, variables that were directly related in the model were also highly correlated (Table 3). Together the pathways accounted for 41% of the variance of PTSD symptoms in children.

**Figure 5.** Path analytic model of the CBCL-PTSD scale reported by fathers



## Discussion

This is one of the few studies that investigate the relationship between parental stress and problem behaviour in burn injured children and the only study, to our knowledge, where parental stress of both the father and the mother is being observed.

Problem behaviour in children with burns was not more prevalent in this study than it is in the general Dutch population. Mothers reported about the same amount of problematic behaviour (7.7%). Fathers on the other hand reported even less problematic behaviour (3.7%) than Koot & Verhulst (1991) suggested in their prevalence research about problem behaviour in the general Dutch population. A substantial number of mothers (12.8%) reported a score of 9 or higher on posttraumatic stress of their child, which indicates that those children met the modified criteria for PTSD. Fathers reported a much lower percentage (3.7%) of children who met the criteria for PTSD.

The results also show that mothers reported high posttraumatic stress scores, especially within the first month after the burn event. As previously described, a score of 26 and higher suggests that parents experience clinically significant problems in the aftermath of the accident (Brom & Kleber, 1985). Mothers have high mean posttraumatic stress scores and although this score decreases significantly in 3 months, it remains at a high level (Joseph, 2000). Fathers experience a medium level of stress immediately after the burn event as well as 3 months later. Notable as well is that mother's guilt feelings about the burn event were not significantly related to stress of the fathers. In turn, the guiltier fathers felt about the burn event, the more stress was experienced by the mothers.

These results raise the question why fathers and mothers experience the burn event in such a different way. Women tend to report higher scores of stress in most cases (Brom & Kleber, 1985). A possibility as well is that mothers have a different way of coping with traumatic experiences than fathers. It is suggested that mothers have an emotion-focused coping style and experience more self blame; fathers on the other hand are more avoidant (Fong, 1997). It could be that the coping style and more self blame of the mothers lead to higher stress scores and more feelings of guilt about the accident,

whereas fathers are more likely to avoid the burn event and experience less feelings of guilt.

Mothers tend to report more posttraumatic stress, feelings of guilt and problematic behaviour of their child, but there were remarkable results found as well when fathers are observed. There were significant correlations between TBSA and feelings of guilt in fathers and between feelings of guilt and the posttraumatic stress of their child. The bigger the burn, the more feelings of guilt a father experienced and the guiltier a father felt, the more problem behaviour was reported. It could be that fathers try to avoid the burn event, but the bigger the burn, the harder it is to avoid it and therefore it can be that fathers feel guiltier about the event. This result is previously suggested in mothers by Bakker et al. (submitted) and Mason (1993), who suggested that remaining scars and feelings of guilt influence stress responses.

The significant relations between TBSA and feelings of guilt and feelings of guilt and the posttraumatic stress in children are observed in Figure 5. These relations indicate direct pathways in the model. Another direct pathway is the relation between parental stress 3 months post-burn and PTSD symptoms in children. This is consistent with previous findings that children's PTSD is directly related to parental PTSD symptoms and vice versa (DeVries et al., 1999; Hall et al., 2006). The question remains why the model did not fit for mothers. Besides a different coping style, mothers may be more susceptible to other sources of stress that were not taken into account in this study, e.g. lack of family support and the extent of stress before the burn event.

Apart from the lack that this study did not take parental coping styles in to account, there are a few other limitations in this study. First, data in this study are derived from an ongoing study and are therefore preliminary outcomes. The study also consists of a small sample size. Second, the measurement of feelings of guilt may have been too narrow. It would be better if feelings of guilt were measured at both points in time, because the measurements could be highly influenced by each other. In addition, it can be argued that a single item might not fully meet the complex concept of guilt. However, it is suggested that lengthening a scale does not always increase and

sometimes actually weakens its validity (Burisch, 1997). Nevertheless, further research is needed to clarify whether it would be better if a broader range of guilt-related aspects is investigated. Third, there is a high reliance on observation of the parents. Parents' state of stress may affect the interpretation of their child's behaviour and emotions (Shemesh et al., 2005). It is possible that parents, who are traumatized themselves, provide data of their children that is biased by their own state of mind. However, Smith et al. (2001) suggest that traumatized, symptomatic parents can report valid data on symptoms of their children.

Apart from the limitations, this study is one of the few studies that investigated the relationship between parental stress and problem behaviour in children with burns and, to our knowledge, the only study that observed fathers as well as mothers. The results yield directions for future research in traumatic stress responses aiming at identifying predictors for parental stress, feelings of guilt and problematic behaviour in children with burns as well as other pediatric injury populations. The remarkable patterns found in fathers' responses are a direction for future research as well.

## References

- Achenbach, T. M., & Edelbrock, C. (Eds.). (1983). *Manual for the Child Behavior Checklist and revised child behavior profile*. Burlington, VT: University of Vermont, Department of Psychiatry.
- Ackerman, P. T., Newton, J. E., McPherson, W. B., Jones, J. G., & Dykman, R. A. (1998). Prevalence of post traumatic stress disorder and other psychiatric diagnoses in three groups of abused children (sexual, physical, and both). *Child Abuse & Neglect, 22*(8), 759-774.
- ADBC. Unpublished results: program of epidemiology of the Association of Dutch Burn Centres.
- APA (Ed.). (2000). *Diagnostic and Statistical Manual of Mental Disorders* (Vol. 4th ed. TR). Washington DC: American Psychiatric Association.
- Bakker, A., Van Loey, N. E. E., Van Son, M. J. M., & Van der Heijden, P. G. M. (submitted). Brief report: Mothers' Long-term Posttraumatic Stress Symptoms Following a Burn Event of Their Child.
- Balluffi, A., Kassam-Adams, N., Kazak, A., Tucker, M., Dominguez, T., & Helfaer, M. (2004). Traumatic stress in parents of children admitted to the pediatric intensive care unit. *Pediatric Critical Care Medicine 5*(6).
- Bentler, P. M., & Chou, C. (Eds.). (1988). *Practical issues in structural modeling*. Newbury Park, CA: Sage.
- Brom, D., & Kleber, R. J. (1985). De Schok Verwerkings Lijst. *Nederlands Tijdschrift voor de Psychologie, 40*, 164-168.
- Burisch, M. (1997). Test length and validity revisited. *European Journal of Personality, 11*, 303-315.
- Caffo, E., & Belaise, C. (2003). Psychological aspects of traumatic injury in children and adolescents. *Child and Adolescent Psychiatric Clinics of North America, 12*(3), 493-535.

- Cella, D. F., Perry, S. W., Kulchycky, S., & Goodwin, C. (1988). Stress and coping in relatives of burn patients: a longitudinal study. *Hospital and Community Psychiatry, 39*(2), 159-166.
- Dehon, C., & Scheeringa, M. S. (2006). Screening for preschool posttraumatic stress disorder with the Child Behavior Checklist. *Journal of Pediatric Psychology, 31*(4), 431-435.
- Denayer, L., Evers-Kiebooms, G., & Van den Berghe, H. (1990). A child with cystic fibrosis: I. Parental knowledge about the genetic transmission of CF and about DNA-diagnostic procedures. *Clinical Genetics, 37*(3), 198-206.
- DeVries, A. P., Kassam-Adams, N., Cnaan, A., Sherman-Slate, E., Gallagher, P. R., & Winston, F. K. (1999). Looking beyond the physical injury: posttraumatic stress disorder in children and parents after pediatric traffic injury. *Pediatrics, 104*(6), 1293-1299.
- El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006). Depression in mothers of burned children. *Archives of Women's Mental Health, 9*(3), 117-119.
- Fong, J. (1997). A study of self-monitoring processes and coping behaviour in burns victims. *Burns, 23 Suppl 1*, S8-11.
- Fukunishi, I. (1998). Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. *Psychological Reports, 83*(1), 331-335.
- Gorga, D., Johnson, J., Bentley, A., Silverberg, R., Glassman, M., Madden, M., et al. (1999). The physical, functional, and developmental outcome of pediatric burn survivors from 1 to 12 months postinjury. *The Journal of Burn Care & Rehabilitation, 20*(2), 171-178; discussion 170.
- Green, B. L., Korol, M., Grace, M. C., Vary, M. G., Leonard, A. C., Gleser, G. C., et al. (1991). Children and disaster: age, gender, and parental effects on PTSD symptoms. *Journal of the American Academy of Child and Adolescent Psychiatry, 30*(6), 945-951.

- Hall, E., Saxe, G., Stoddard, F., Kaplow, J., Koenen, K., Chawla, N., et al. (2006). Posttraumatic stress symptoms in parents of children with acute burns. *Journal of Pediatric Psychology, 31*(4), 403-412.
- Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: a measure of subjective stress. *Psychosomatic Medicine, 41*(3), 209-218.
- Joseph, S. (2000). Psychometric evaluation of Horowitz's Impact of Event Scale: a review. *Journal of Traumatic Stress, 13*(1), 101-113.
- Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 31*(4), 343-355.
- Kent, L., King, H., & Cochrane, R. (2000). Maternal and child psychological sequelae in paediatric burn injuries. *Burns, 26*(4), 317-322.
- Koot, H. M., Van Den Oord, E. J., Verhulst, F. C., & Boomsma, D. I. (1997). Behavioral and emotional problems in young preschoolers: cross-cultural testing of the validity of the Child Behavior Checklist/2-3. *Journal of Abnormal Child Psychology, 25*(3), 183-196.
- Koot, H. M., & Verhulst, F. C. (1991). Prevalence of problem behavior in Dutch children aged 2-3. *Acta Psychiatrica Scandinavica, 367*, 1-37.
- LeDoux, J., Meyer, W. J., 3rd, Blakeney, P. E., & Herndon, D. N. (1998). Relationship between parental emotional states, family environment and the behavioural adjustment of pediatric burn survivors. *Burns, 24*(5), 425-432.
- Lee, D. A., Scragg, P., & Turner, S. (2001). The role of shame and guilt in traumatic events: a clinical model of shame-based and guilt-based PTSD. *The British Journal of Medical Psychology, 74*(Pt 4), 451-466.
- Liber, J. M., List, D., Van Loey, N. E., & Kef, S. (2006). Internalizing problem behavior and family environment of children with burns: a Dutch pilot study. *Burns, 32*(2), 165-171.
- Mason, S. A. (1993). Young, scarred children and their mothers - a short-term investigation into the practical, psychological and social implications of thermal

- injury to the preschool child. Part I: Implications for the mother. *Burns*, 19(6), 495-500.
- Meyer, W. J., Blakeney, P., Moore, P., Murphy, L., Robson, M., & Herndon, D. (1994). Parental well-being and behavioral adjustment of pediatric survivors of burns. *The Journal of Burn Care & Rehabilitation*, 15(1), 62-68.
- Nugent, N. R., Ostrowski, S., Christopher, N. C., & Delahanty, D. L. (2007). Parental posttraumatic stress symptoms as a moderator of child's acute biological response and subsequent posttraumatic stress symptoms in pediatric injury patients. *Journal of Pediatric Psychology*, 32(3), 309-318.
- Pine, D. S., & Cohen, J. A. (2002). Trauma in children and adolescents: risk and treatment of psychiatric sequelae. *Biological Psychiatry*, 51(7), 519-531.
- Rizzone, L. P., Stoddard, F. J., Murphy, J. M., & Kruger, L. J. (1994). Posttraumatic stress disorder in mothers of children and adolescents with burns. *The Journal of Burn Care & Rehabilitation*, 15(2), 158-163.
- Roddenberry, A., & Renk, K. (2008). Quality of Life in Pediatric Cancer Patients: The Relationship Among Parents' Characteristics, Children's Characteristics, and Informant Concordance. *Journal of Children and Family Studies*, 17, 402-426e.
- Roseman, I. J., Spindel, M. S., & Jose, P. E. (1990). Appraisals of Emotion-Eliciting Events: Testing a Theory of Discrete Emotions. *Journal of Personality and Social Psychology*, 59(5), 899-915.
- Scheeringa, M. S., Zeanah, C. H., Drell, M. J., & Larrieu, J. A. (1995). Two approaches to the diagnosis of posttraumatic stress disorder in infancy and early childhood. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34(2), 191-200.
- Shemesh, E., Newcorn, J. H., Rockmore, L., Shneider, B. L., Emre, S., Gelb, B. D., et al. (2005). Comparison of parent and child reports of emotional trauma symptoms in pediatric outpatient settings. *Pediatrics*, 115(5), e582-589.

- Smith, P., Perrin, S., Yule, W., & Rabe-Hesketh, S. (2001). War exposure and maternal reactions in the psychological adjustment of children from Bosnia-Herzegovina. *Journal of Child Psychology and Psychiatry, 42*(3), 395-404.
- Stoddard, F. J., & Saxe, G. (2001). Ten-year research review of physical injuries. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(10), 1128-1145.
- Stoddard, F. J., Saxe, G., Ronfeldt, H., Drake, J. E., Burns, J., Edgren, C., et al. (2006). Acute stress symptoms in young children with burns. *Journal of the American Academy of Child and Adolescent Psychiatry, 45*(1), 87-93.
- Terr, L. (1988). What happens to early memories of trauma? A study of twenty children under age five at the time of documented traumatic events. *Journal of the American Academy of Child and Adolescent Psychiatry, 27*(1), 96-104.
- Van der Ploeg, E., Mooren, T. T., Kleber, R. J., Van der Velden, P. G., & Brom, D. (2004). Construct validation of the Dutch version of the impact of event scale. *Psychological Assessment, 16*(1), 16-26.
- Woodward, J. (1959). Emotional disturbances of burned children. *British Medical Journal, 1*(5128), 1009-1013.
- Wright, L., & Fulwiler, R. (1974). Long range emotional sequelae of burns: effects on children and their mothers. *Pediatric Research, 8*(12), 931-934.
- Yehuda, R., Halligan, S. L., & Bierer, L. M. (2002). Cortisol levels in adult offspring of Holocaust survivors: relation to PTSD symptom severity in the parent and child. *Psychoneuroendocrinology, 27*(1-2), 171-180.
- Yehuda, R., Halligan, S. L., & Grossman, R. (2001). Childhood trauma and risk for PTSD: relationship to intergenerational effects of trauma, parental PTSD, and cortisol excretion. *Development and Psychopathology, 13*(3), 733-753.
- Yule, W. (2001). Posttraumatic stress disorder in the general population and in children. *The Journal of Clinical Psychiatry, 62 Suppl 17*, 23-28.

## **Appendix 1**

*Information letter for parents of children with burns (Dutch)*

## **Informatiebrief voor ouders van kinderen met brandwonden**

**Titel van het onderzoek:** Gedragsproblemen en kwaliteit van leven bij kinderen met brandwonden.

Geachte heer/mevrouw,

U bent gevraagd om mee te doen aan de medisch-wetenschappelijke studie "Gedragsproblemen en levenskwaliteit bij kinderen met brandwonden". Om te beoordelen of u mee wilt doen, is goede voorlichting van onze kant nodig, en een zorgvuldige afweging van uw kant. Vandaar dat u deze schriftelijke informatie ontvangt. U kunt deze rustig (her)lezen en in eigen kring bespreken. Ook daarna kunt u nog altijd vragen stellen aan de artsen/onderzoekers die aan het eind van deze informatie staan genoemd.

### **Achtergrond en doel van het onderzoek**

Wanneer uw kind opgenomen wordt in het ziekenhuis voor de behandeling van brandwonden, kan dat voor u en uw kind een ingrijpende gebeurtenis zijn. Het is mogelijk dat uw kind (tijdelijk) anders reageert dan u gewend bent of dat de opname van uw kind voor u de nodige stress oplevert. Dat alles zorgt ervoor dat brandwonden nog een hele tijd een stempel kunnen drukken op het functioneren van uzelf en/of uw kind. Een goede opvang en begeleiding is dan ook erg belangrijk.

De brandwondencentra is er alles aan gelegen om de zorg voor en hulp aan kinderen met brandwonden en hun ouders zo goed mogelijk te laten verlopen. Om een duidelijker beeld te krijgen van de problemen, welke het doel is van dit onderzoek, vragen wij **uw medewerking**. We onderzoeken **hoeveel kinderen** er na het oplopen van de brandwonden te maken krijgen met **veranderingen in zijn/haar leven** (ander gedrag dan u gewend bent), **hoe het verloop ervan is** en **waar die veranderingen mee samenhangen** (bijv. hoe u omgaat met ingrijpende gebeurtenissen). We onderzoeken ook de mate van **stress die door de ouders ervaren wordt**.

Dit onderzoek gebeurt in zes brandwondencentra in Nederland en België.

### **Hoe wordt het onderzoek uitgevoerd en wat wordt er van u verwacht?**

Wij vragen beide ouders op een aantal tijdstippen **vragenlijsten** in te vullen. De vragenlijsten gaan over uiteenlopende onderwerpen en kunnen confronterend zijn. Sommige vragenlijsten gaan heel **algemeen** over het gedrag van uw kind, over hoe u omgaat met gebeurtenissen in het algemeen, en de mate van stress die u ervaart. Andere vragenlijsten gaan **speciaal** over de brandwonden of over uw gedachten aan het ongeval en de toedracht ervan. In de loop van de eerste maand krijgt u een aantal vragenlijsten.

De eerste lijst vult u samen met de onderzoeker in. Daarna ontvangt u vier keer vragenlijsten: na 3, 6, 12 en 18 maanden. Het invullen van de vragenlijsten zal ongeveer 15 tot 60 minuten in beslag nemen. De onderzoeker van het brandwondencentrum stuurt deze op naar uw huisadres. Wij vragen u deze binnen 2 weken ingevuld terug te sturen. Wanneer de lijsten na 3 weken niet terug zijn, neemt de onderzoeker telefonisch of per e-mail contact met u op. Er zijn voor u geen kosten verbonden aan uw deelname aan dit onderzoek. De duur van het onderzoek is in principe **1,5 jaar**.

### **Wat zijn de mogelijke voor- en nadelen van deelname aan dit onderzoek?**

U heeft zelf geen voordeel van deelname aan deze studie. De resultaten van dit onderzoek worden in de toekomst ten dienste gesteld aan hulpverleners in de brandwondencentra waardoor zij beter kunnen inspelen op de specifieke zorgbehoeften van kinderen met brandwonden.

### **Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?**

Uw deelname aan dit onderzoek is geheel **vrijwillig**: u kunt altijd, zonder vermelding van reden, uw verdere medewerking afbreken. Uw beslissing om niet deel te nemen zal geen enkele invloed hebben op de behandeling of begeleiding van uw kind. Ook als u nu

toestemming geeft, kunt u die te allen tijde zonder opgave van redenen weer intrekken. Als uw welbevinden in gevaar is, beëindigt de onderzoeker uw deelname aan het wetenschappelijk onderzoek direct.

### **Verzekering**

De opdrachtgever van dit onderzoek heeft van de Stichting Beoordeling Ethiek Biomedisch Onderzoek ontheffing gekregen van de verplichting een verzekering af te sluiten die de door het onderzoek veroorzaakte schade van de proefpersoon dekt. De reden van deze ontheffing is dat de commissie van oordeel is dat dit onderzoek voor de proefpersoon naar zijn aard zonder enig risico is.

### **Wat gebeurt er met uw gegevens?**

Om de onderzoeksinformatie te kunnen verwerken verzamelen we een aantal persoonlijke gegevens. U kunt erop rekenen dat deze **strikt vertrouwelijk** behandeld worden. Tot uw persoon herleidbare gegevens kunnen slechts met uw toestemming (aan te geven op het toestemmingsformulier) door derden worden ingezien. En dan ook alleen als zij hiertoe bevoegd zijn, zoals medewerkers van het onderzoeksteam, medewerkers van de Inspectie voor de Gezondheidszorg (IGZ) of bevoegde inspecteurs van een buitenlandse overheid, en leden van de Medisch Ethische Toetsingscommissie. Inzage kan nodig zijn om de betrouwbaarheid en kwaliteit van het onderzoek na te gaan. Onderzoeksgegevens worden gehanteerd met inachtneming van de Wet Bescherming Persoonsgegevens. De onderzoeker neemt kennis van uw antwoorden maar de verwerking van gegevens gebeurt anoniem. Persoonsgegevens die tijdens de studie worden verzameld, worden vervangen door een codenummer. Alleen dat nummer wordt gebruikt voor studiedocumentatie, in rapporten of publicaties over dit onderzoek. Enkel de onderzoeker heeft de sleutel van de code en weet wie de persoon achter het codenummer is.

### **Zijn er extra kosten wanneer u besluit aan dit onderzoek mee te doen?**

Er zijn voor u geen kosten aan het onderzoek verbonden.

### **Is het onderzoek goedgekeurd door een medisch-ethische toetsingscommissie?**

Voor dit onderzoek is goedkeuring verkregen van de Stichting Beoordeling Ethiek Biomedisch Onderzoek..

De voor dit onderzoek geldende nationale en internationale richtlijnen worden nauwkeurig in acht genomen.

### **Wilt u verder nog iets weten?**

Neem rustig de tijd om uw medewerking te overwegen. Na uiterlijk 8 dagen willen we graag antwoord.

Mocht u nog vragen hebben dan kunt u die bespreken met de mw. X, de onderzoeker van het brandwondencentrum, tel. X. Als u twijfelt over deelname of u hebt vragen die u liever niet aan de onderzoeker stelt, dan kunt u iemand raadplegen die niet betrokken is bij het onderzoek maar wel deskundig is op dit gebied. Dit is dr. X, chirurg van het brandwondencentrum, tel. X.

## **Appendix 2**

*Informed consent form for both parents/guardians (Dutch)*

## Toestemmingsformulier voor de beide ouders/voogd

Titel van het onderzoek: Gedragsproblemen en levenskwaliteit bij kinderen met brandwonden.

Mij is gevraagd toestemming te verlenen voor deelname aan bovengenoemd medisch wetenschappelijk onderzoek ten behoeve van:

Naam kind: \_\_\_\_\_ Geboortedatum: \_\_ / \_\_ / \_\_

Ik bevestig, dat ik de informatiebrief voor ouders (versie 04, 22 mei 2008) heb gelezen. Ik heb de gelegenheid gehad om aanvullende vragen te stellen. Deze vragen zijn naar tevredenheid beantwoord. Ik heb voldoende tijd gehad om over deelname van mijn kind na te denken.

Ik weet dat deelname geheel vrijwillig is en dat ik mijn toestemming op ieder moment kan intrekken zonder dat ik daarvoor een reden hoeft te geven.

Ik geef toestemming dat bevoegde personen, medewerkers van de Inspectie voor de Gezondheidszorg, bevoegde inspecteurs van een buitenlandse overheid of leden van de medisch-ethische toetsingscommissie inzage kunnen krijgen in de medische gegevens en onderzoeksgegevens van mijn kind.

Ik geef toestemming om de gegevens te verwerken voor de doelen zoals beschreven in de informatiebrief.

Ik geef wel/geen\* toestemming om de gegevens gedurende maximaal 15 jaar na afloop van de studie te bewaren.

Ik geef toestemming voor deelname van mijn kind aan bovengenoemd onderzoek.

Naam ouders/voogd\*\*:  
Datum: \_\_ / \_\_ / \_\_

Handtekening:

Naam ouders/voogd\*\*:  
Datum: \_\_ / \_\_ / \_\_

Handtekening:

---

Ik verklaar hierbij bovengenoemde persoon/personen volledig geïnformeerd te hebben over het genoemde onderzoek.

Naam onderzoeker: \_\_\_\_\_ Handtekening: \_\_\_\_\_ Datum: \_\_  
/ \_\_ / \_\_

---

Aanvullende informatie is gegeven door (indien van toepassing):

Naam \_\_\_\_\_  
Functie \_\_\_\_\_

Handtekening \_\_\_\_\_ Datum: \_\_/\_\_/\_\_

\* Doorhalen wat niet van toepassing is. \*\* Dit formulier moet worden ondertekend door de ouders die het gezag uitoefenen of de voogd, wanneer het kind jonger dan 18 jaar is. Voor kinderen van 12 t/m 17 jaar, die wilsbekwaam zijn, moet tevens formulier A door het kind worden ondertekend.

### **Appendix 3**

*Child Behaviour Checklist (CBCL) for 1.5/5 years (Dutch)*



# GEDRAGSVRAGENLIJST VOOR KINDEREN VAN 1½-5 JAAR

Graag met blokletters invullen.

NAAM Voornaam _____ Achternaam _____ KIND		SOORT WERK VAN DE OUDERS, ook al werkt u op dit moment niet (zo duidelijk mogelijk, bijvoorbeeld: automonteur, leraar, secretaresse enz.) SOORT WERK VADER: _____ SOORT WERK MOEDER: _____
GESLACHT KIND <input type="checkbox"/> Jongen <input type="checkbox"/> Meisje	LEEFTIJD KIND _____	Deze vragenlijst werd ingevuld door (graag uw volledige naam opschrijven): _____
DATUM VAN VANDAAG Dag _____ Maand _____ Jaar _____	GEBOORTEDATUM KIND Dag _____ Maand _____ Jaar _____	Uw geslacht: <input type="checkbox"/> Man <input type="checkbox"/> Vrouw Uw relatie tot dit kind: <input type="checkbox"/> Biologische ouder <input type="checkbox"/> Stiefouder <input type="checkbox"/> Grootouder <input type="checkbox"/> Adoptieouder <input type="checkbox"/> Pleegouder <input type="checkbox"/> Anders (Schrijf op): _____

Dit formulier invullen zoals u dit kind ziet, ook al komt dat niet overeen met wat anderen vinden. Voelt u zich vrij om naast elke vraag, of onderaan bladzijde 2, eventueel aanvullende informatie te geven.  
**Graag alle vragen beantwoorden.**

Hieronder is een lijst met vragen over kinderen. Alle vragen gaan over hoe dit kind **nu is of in de afgelopen 2 maanden** is geweest. Maak een rondje om de ② als de vraag **duidelijk of vaak** bij dit kind past. Maak een rondje om de ① als de vraag een **beetje of soms** bij dit kind past. Als de vraag **helemaal niet** bij dit kind past, maak dan een rondje om de ①. Beantwoord alle vragen zo goed als u kunt, ook al lijken sommige vragen niet bij dit kind te passen.

**0 = Helemaal Niet (voor zover u weet)      1 = een Beetje of Soms      2 = Duidelijk of Vaak**

0 1 2	1. Pijnklachten (zonder medische oorzaak, <b>geen</b> buikpijn of hoofdpijn)	0 1 2	24. Eet niet goed (schrijf op): _____
0 1 2	2. Doet te jong voor zijn/haar leeftijd	0 1 2	25. Kan niet opschieten met andere kinderen
0 1 2	3. Is bang om iets nieuws te proberen	0 1 2	26. Kan geen pret maken, doet als een kleine volwassene
0 1 2	4. Vermijdt anderen aan te kijken	0 1 2	27. Lijkt zich niet schuldig te voelen na zich misdragen te hebben
0 1 2	5. Kan zich niet concentreren, kan niet lang de aandacht ergens bij houden	0 1 2	28. Wil het huis niet uit
0 1 2	6. Kan niet stilzitten, is onrustig of hyperactief	0 1 2	29. Snel van streek als iets tegenzit
0 1 2	7. Kan er niet tegen wanneer dingen ergens anders staan	0 1 2	30. Snel jaloers
0 1 2	8. Kan niet tegen wachten, alles moet nu gebeuren	0 1 2	31. Eet of drinkt dingen die eigenlijk niet eetbaar of drinkbaar zijn – snoep <b>niet</b> meetellen (schrijf op): _____
0 1 2	9. Kauwt op dingen die niet eetbaar zijn	0 1 2	32. Is bang voor bepaalde dieren, situaties of plaatsen (schrijf op): _____
0 1 2	10. Klampt zich vast aan volwassenen of is te afhankelijk	0 1 2	33. Voelt zich snel beledigd of gekwetst
0 1 2	11. Zoekt voortdurend hulp	0 1 2	34. Bezeert zich vaak, krijgt vaak ongelukken
0 1 2	12. Obstipatie, heeft geen ontlasting (zonder dat hij/zij ziek is)	0 1 2	35. Vecht veel
0 1 2	13. Huilt veel	0 1 2	36. Bemoeit zich met alles
0 1 2	14. Wreed tegen dieren	0 1 2	37. Raakt te veel overstuurd wanneer hij/zij gescheiden wordt van zijn/haar ouders
0 1 2	15. Uitdagend	0 1 2	38. Heeft moeite met inslapen
0 1 2	16. Wil in alles direct zijn/haar zin hebben	0 1 2	39. Hoofdpijnen (zonder medische oorzaak)
0 1 2	17. Vernielt eigen spullen	0 1 2	40. Slaat anderen
0 1 2	18. Vernielt spullen van gezinsleden of van andere kinderen	0 1 2	41. Houdt zijn/haar adem in
0 1 2	19. Diarree of dunne ontlasting (zonder dat hij/zij ziek is)	0 1 2	42. Doet dieren of mensen zonder opzet pijn
0 1 2	20. Ongehoorzaam	0 1 2	43. Ziet er ongelukkig uit zonder duidelijke reden
0 1 2	21. Verstoord wanneer iets anders gaat dan hij/zij gewend is	0 1 2	44. Boze buien
0 1 2	22. Wil niet alleen slapen		
0 1 2	23. Geeft geen antwoord wanneer anderen tegen hem/haar praten		

**Kijk na of u alle vragen hebt beantwoord. Ga dan verder met de volgende bladzijde.**

0 = Helemaal Niet (voor zover u weet)

1 = een Beetje of Soms

2 = Duidelijk of Vaak

- 0 1 2 45. Misselijk (zonder medische oorzaak)
- 0 1 2 46. Zenuwachtige bewegingen of zenuwtrekken  
(schrijf op): \_\_\_\_\_
- 0 1 2 47. Nerveus, zenuwachtig of gespannen
- 0 1 2 48. Nachtmerries
- 0 1 2 49. Eet te veel
- 0 1 2 50. Is erg moe
- 0 1 2 51. Is in paniek zonder duidelijke reden
- 0 1 2 52. Pijnlijke ontlasting (zonder medische oorzaak)
- 0 1 2 53. Valt mensen lichamelijk aan
- 0 1 2 54. Pukt aan neus, huid of aan iets anders van het  
lichaam (schrijf op): \_\_\_\_\_
- 0 1 2 -55. Speelt te veel met eigen geslachtsdelen
- 0 1 2 56. Onhandig of stuntelig
- 0 1 2 57. Oogproblemen (zonder medische oorzaak)  
(schrijf op): \_\_\_\_\_
- 0 1 2 58. Straffen verandert zijn/haar gedrag niet
- 0 1 2 59. Gaat snel over van de ene bezigheid naar de  
andere
- 0 1 2 60. Huiduitslag of andere huidproblemen (zonder  
medische oorzaak)
- 0 1 2 61. Weigert om te eten
- 0 1 2 62. Weigert om actieve spelletjes te spelen
- 0 1 2 63. Bonkt steeds met hoofd of wiegt met lichaam
- 0 1 2 64. Verzet zich 's avonds met naar bed gaan
- 0 1 2 65. Verzet zich tegen zindelijk worden (schrijf op):  
\_\_\_\_\_
- 0 1 2 66. Schreeuwt veel
- 0 1 2 67. Lijkt niet te reageren op liefde of genegenheid
- 0 1 2 68. Schaamt zich gauw of voelt zich niet op zijn/haar  
gemak
- 0 1 2 69. Egoïstisch, wil niet delen
- 0 1 2 70. Toont weinig liefde of genegenheid voor anderen
- 0 1 2 71. Toont weinig belangstelling voor dingen om zich  
heen
- 0 1 2 72. Toont te weinig angst om zich te bezeren

- 0 1 2 73. Te verlegen of timide
- 0 1 2 74. Slaapt overdag en/of 's nachts minder dan de  
meeste kinderen (schrijf op): \_\_\_\_\_
- 0 1 2 75. Smeert of speelt met ontlasting
- 0 1 2 76. Spraakprobleem (schrijf op): \_\_\_\_\_
- 0 1 2 77. Staart voor zich uit of lijkt volledig in beslag  
genomen
- 0 1 2 78. Buikpijn of krampen (zonder medische oorzaak)
- 0 1 2 79. Snelle wisselingen tussen verdriet en opwinding
- 0 1 2 80. Vreemd gedrag (schrijf op): \_\_\_\_\_
- 0 1 2 81. Koppig, stuurs of prikkelbaar
- 0 1 2 82. Stemming en gevoelens veranderen plotseling
- 0 1 2 83. Mocht veel
- 0 1 2 84. Praat of schreeuwt in slaap
- 0 1 2 85. Driftbuien of snel driftig
- 0 1 2 86. Overdreven netjes of te schoon
- 0 1 2 87. Te angstig of te bang
- 0 1 2 88. Werkt niet mee
- 0 1 2 89. Weinig actief, beweegt zich langzaam of te  
weinig energie
- 0 1 2 90. Ongelukkig, verdrietig of depressief
- 0 1 2 91. Meer dan gewoon luidruchtig
- 0 1 2 92. Van streek door onbekende mensen of situaties  
(schrijf op): \_\_\_\_\_
- 0 1 2 93. Overgeven (zonder medische oorzaak)
- 0 1 2 94. Wordt 's nachts vaak wakker
- 0 1 2 95. Loopt weg
- 0 1 2 96. Wil veel aandacht
- 0 1 2 97. Zeuren
- 0 1 2 98. Teruggetrokken, gaat niet met anderen om
- 0 1 2 99. Maakt zich zorgen
100. Schrijf hier ieder ander probleem op dat het kind  
heeft en dat hierboven nog niet genoemd is:
- 0 1 2 \_\_\_\_\_
- 0 1 2 \_\_\_\_\_
- 0 1 2 \_\_\_\_\_

Heeft het kind een lichamelijke of verstandelijke handicap?

Nee

Ja – graag opschrijven:

Waarover maakt u zich het meest zorgen wat dit kind betreft?

Waarover bent u het meest tevreden wat dit kind betreft?

## **Appendix 4**

*Impact of Event Scale (Dutch)*

# SVL-ouders

Uw kind heeft brandwonden opgelopen waarvoor het moest worden opgenomen in het ziekenhuis. Ook voor ouders is dat een ingrijpende gebeurtenis. Misschien ervaart u nog regelmatig de gevolgen van wat er met uw kind is gebeurd.

Hieronder vindt u een lijst met 15 uitspraken. Neem wat er met uw kind is gebeurd in gedachten en geef aan **HOE VAAK** u de beschreven reactie **DE AFGELOPEN ZEVEN DAGEN** en **VANDAAG** hebt ervaren.

Datum: .....

	helemaal niet	zelden	soms	vaak
1. Ik denk aan wat er gebeurd is zonder dat ik het wil	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Ik zorg ervoor niet van streek te raken, als ik eraan denk of eraan herinnerd word	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Ik probeer de gebeurtenis uit mijn herinnering te bannen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Ik kan moeilijk in slaap vallen of in slaap blijven omdat beelden en gedachten erover door mijn hoofd gaan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Bij vlagen heb ik er sterke gevoelens over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Ik droom erover	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Ik blijf dingen die me eraan herinneren uit de weg gaan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Ik heb het gevoel alsof het niet echt gebeurd is, alsof het niet echt is	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Ik probeer er niet over te praten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Beelden erover schieten me in gedachten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Andere dingen doen me er steeds weer aan denken	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Ik weet dat ik er nog heel wat gevoelens over heb, maar houd er geen rekening mee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Ik probeer er niet aan te denken	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Iedere herinnering brengt de gevoelens weer terug	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Mijn gevoel erover is als het ware verdoofd	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Appendix 5**

*Schematic view of the questionnaires at different measurements*

**Appendix 5.** Schematic view of the questionnaires at different measurements

