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Posttraumatic stress disorder in mothers of children who have undergone surgery for congenital disease at a pediatric surgery department

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Abstract

Purpose: The aim of the study was to investigate posttraumatic stress disorder (PTSD) in mothers of children who have undergone surgery for congenital disease at a pediatric surgery department.

Methods: A questionnaire survey was carried out in 145 mothers of children who had undergone surgery and were still alive. For comparison, the mothers were categorized into 3 groups according to the severity of their child's disease.

Results: Of the 145 mothers, 29 (20%) were likely to be diagnosed as having developed PTSD at the time of the survey. Posttraumatic stress disorder symptoms correlated with factors such as anxiety and condition of the child. In terms of the disease severity of the child, factors such as anxiety tended to be observed more frequently in the higher disease severity group, whereas the proportion of mothers likely to be diagnosed as having developed PTSD was smallest in the moderate-severity group.

Conclusions: Twenty percent of the mothers of children had probably developed PTSD. In the moderate-severity group, there seemed to be a factor that alleviated PTSD symptoms. Because mothers provided effective care for the symptoms of children in the moderate-severity group, this observation suggests that participation of the mother in their child's treatment might prevent them from developing PTSD symptoms.

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In pediatric medicine, as the survival of life-threatening, intractable disease has improved, the psychology of the survivors has been more actively surveyed [1-4]. Recently, the psychological problems of survivors have been

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Table 1 Main triad of PTSD

Reexperience: Thoughts keep coming back to mind in order for the person to try and make sense of what happened. For example, recurrent and intrusive distressing recollections of the event, including images, thoughts, and recurrent distressing dreams of the event, acting or feeling as though the traumatic event were recurring.
Avoidance: Means of coping with the high levels of distress associated with the intrusive memories and numbing of general responsiveness. For example, efforts to avoid thoughts, feelings, or conversations associated with the trauma; efforts to avoid activities, places, or people that arouse recollections of the trauma; and inability to recall an important aspect of the trauma and/or markedly diminished interest or participation in significant activities, feeling of detachment or estrangement from others, and restricted range of effect.
Arousal: The body and mind staying on alert to ensure that no future threat goes undetected, as indicated. For example, difficulty falling or staying asleep, irritability or outbursts of anger, exaggerated startle response.

increasingly understood as posttraumatic stress disorder (PTSD) [5-12]. Posttraumatic stress disorder is a syndrome that continuously exhibits a series of symptoms of reexperience, avoidance, and arousal after a life-threatening traumatic event (Table 1) [12].

Posttraumatic stress disorder in survivors of serious disease has been investigated mainly in the field of pediatric cancer. It is now considered, however, that a series of events associated with disease and treatment could be "traumatic events for the people close to the survivors," and it has been shown that family members of the survivors suffer for a long time [7-12]. A number of studies have shown that PTSD onset rates are not significantly different between survivors and healthy children, but they are significantly higher in family members of the survivors, especially their mothers [11,12]. In addition, it has been demonstrated that PTSD symptoms in the family members are influenced by a lack of support from the people around and by poor family functioning [7-9], and it has been suggested that PTSD symptoms may greatly influence the adaptation of survivors in the long term [10].

Recently, it has been reported that unexpected admission to the intensive care unit, organ transplant, and burns in children cause similar psychological problems in the mothers of children after treatment [13-15]. However, few studies have investigated PTSD of the family of affected children in the field of pediatric surgery except for accidental trauma and organ transplant. In cases that require surgery soon after birth for congenital disorders, it is thought that family members of the children suffer a great psychological shock, and the possibility that they might develop PTSD cannot be ignored. The psychology of the mothers of children who have undergone surgery for congenital disease has been surveyed in our hospital. Most of them showed marked anxiety and depression [16], and thus here it was considered necessary to investigate these problems from the aspect of PTSD.

1. Aims

The aims of this study were to clarify whether PTSD occurs in the mothers of children who have undergone surgery for congenital disease in the field of pediatric surgery and, if it is present, what percentage of PTSD is observed; and the pediatric surgery–specific factors that affect psychological and physiological problems in the mothers.

2. Subjects

The subjects comprised 225 mothers of children who had undergone surgery for congenital disease at the Pediatric Surgery Department, Tohoku University, between January 1995 and July 2005. Letters were sent to 225 mothers for the survey and 145 of them gave informed consent to participation in the study (response rate, 64.4%). This study was approved by the Ethical Committee of Tohoku University Medical School and was carried out from January to April in 2006. The mothers had no history of physical or mental disorder, and they had received basic education in Japan.

Eight congenital diseases were included in this study: inguinal hernia, anal atresia, Hirschsprung disease, esophageal atresia, biliary atresia, diaphragmatic hernia, exomphalos, and gastroschisis. For a survey of disease characteristics in the field of pediatric surgery, disease severity in the affected children was classified into 3 groups.

Group 1. Good prognosis—diseases are not fatal and a cure is expected from one operation (eg, inguinal hernia).

Table 2 Percentages of participants, Mean age of mothers and Mean time since first explanation of disease and operation

	Subjects	Participants (%)	Mean age of mother (SD; y)	Mean time since first explanation of disease and operation (SD; mo)
Total	225	145 (64.4)	34.84 (±6.29)	54.87 (±36.74) (median, 48)
Group 1	84	44 (52.3)	34.67 (±3.80)	38.84 (±29.18) (median, 35 mo)
Group 2	49	29 (59.1)	36.21 (±5.67)	52.43 (±38.11) (median, 38)
Group 3	92	72 (78.2)	34.39 (±7.59)	66.09 (±36.98) (median, 69 mo)

Group 2. Diseases are rarely fatal, but persistent impairment is likely to remain. A long-term follow-up at the pediatric surgery department is required (mostly, anal atresia and Hirschsprung disease).
Group 3. Diseases are sometimes fatal or a poor prognosis is expected. A long-term follow-up is required at the pediatric surgery department (mostly, esophageal atresia, biliary atresia, diaphragmatic hernia, exomphalos, and gastroschisis).

When 2 diseases or more were concomitantly present, such cases were categorized into the group corresponding to the more severe disease. For each group, the number of subjects, age distribution, mail response rates, and duration from operation are shown in Table 2.

Questionnaires on psychology were received from 145 mothers giving informed consent to participation in the study. The collected data were statistically analyzed using SPSS (SPSS, Chicago, Ill).

3. Methods

3.1. Japanese-language version of the Impact of Event ScaleRevised

The Japanese-language version of the Impact of Event Scale—Revised (IES-R-J), a questionnaire on PTSD symptoms, has been standardized by Asukai et al [17]. It was translated into Japanese after revision of the IES-R by Weiss and Marmar [18]. It is a self-assessment questionnaire consisting of 22 questions, by which 3 major PTSD symptoms (reexperience, avoidance, and arousal) in the past week are graded according to a 5-grade scale from 0 (none) to 4 (markedly present). The cutoff point is set at 25 points. In this study, the symptoms were evaluated under the condition that the first explanation of the disease, and surgery was the traumatic event for the mothers.

3.2. State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory (STAI), a 40-item self-report scale, assesses anxiety symptoms with regard to both current symptoms (state) and personality (trait) [19]. Test-retest reliability is low for the state scale and high for the trait scale, as predicted. The STAI has high internal consistency, adequate construct, and discriminative validity across diverse samples [20]. Higher scores reflect more anxiety.

3.3. Questionnaire on other factors (see Appendix A)

A third questionnaire consisting of 15 self-assessment questions was also used. It was designed to ask questions about factors that would affect the psychology of the mothers, such as their understanding of the disease of their child, their current condition, and the support for the mothers. It was constructed by 2 psychiatrists, 2 pediatric surgeons, and 2 clinical psychotherapists with 10 or more years of clinical experience at the Tohoku University Hospital.

Table 3 Factors that strongly related to the IES-R-J score (Spearman)

	r	P
STAI-I score	0.658	<.01
STAI-II score	0.590	<.01
Current conditions of the children	−0.351	<.01
Likelihood of future operations	0.297	<.01
Distance from the supporter	0.229	<.01
Disease severity of the child	0.214	<.05
The number of operation	0.163	>.1
Presence of functional impairment in daily life	0.154	>.1
Mother's subjective disease severity of the child	0.153	>.1
Likelihood of recurrence of complication after radical operation	0.141	>.1
Likelihood of persistent functional impairment in daily life	0.131	>.1
Age of mothers	−0.113	>.1
Time since first explanation of disease and operation	0.107	>.1
Mother's subjective comprehension to the operation	−0.071	>.1
Time since last operation	0.066	>.1
Mother's subjective comprehension to the disease	−0.012	>.1

3.4. Statistical analysis

To investigate factors that would affect IES-R-J scores in the mothers, the relationship between STAI scores and factors in the questionnaire was analyzed using Spearman correlation test. In addition, the results of the psychology test on the mothers were compared among the groups categorized by the disease severity of the children, and a P value of less than .05 was regarded as statistically significant. All numerical data are expressed as means ± SD.

4. Results

The average IES-R-J score across all subjects was 15.62 ± 14.9, and 29 (20%) showed scores higher than the cutoff value. Of the factors addressed in the questionnaire, those with a strong correlation with IES-R-J scores by Spearman correlation test were as follows (from the highest correlation coefficient): STAI-I ($r = 0.658$, $P < .01$), STAI-II ($r = 0.590$, $P < .01$), "current condition of the child" ($r = -0.351$, $P < .01$), "likelihood of future operations" ($r = 0.297$, $P < .01$), "distance from the supporter" ($r = 0.229$, $P < .01$), and "disease severity of the child" ($r = 0.214$, $P < .05$) (Table 3).

Table 4 The scores of factors that strongly correlated with IES-R-J scores (mean score ± SD)

	Total (n = 145)	Group 1 (n = 44)	Group 2 (n = 29)	Group 3 (n = 72)	Mann-Whitney
IES-R-J	15.62 (±14.90)	12.51 (±13.31)	13.34 (±15.45)	18.39 (±15.24)	Groups 1-3, $P < .05$
STAI-I	41.67 (±11.30)	38.33 (±10.73)	39.86 (±10.47)	44.39 (±11.42)	Groups 1-3, $P < .05$
STAI-II	44.59 (±12.24)	40.74 (±11.70)	43.54 (±12.33)	47.31 (±12.24)	Groups 1-3, $P < .01$
Distance from the supporter	1.56 (±0.80)	1.60 (±0.77)	1.38 (±0.68)	1.61 (±0.87)	No significant difference
Current conditions of the children	3.55 (±0.67)	3.77 (±0.47)	3.46 (±0.74)	3.44 (±0.71)	Groups 1-3, $P < .01$
Likelihood of future operations	0.78 (±0.82)	0.38 (±0.54)	0.61 (±0.74)	1.08 (±0.87)	Groups 1-3, $P < .01$

4.1. Classification according to disease severity

Three groups classified by the disease severity of the child were compared. Mann-Whitney test revealed no significant difference in the age of the mothers or in the factor "distance from the supporter," as answered in the questionnaire. The scores of IES-R-J, STAI-I, STAI-II, and "likelihood of future operations" tended to be higher and "current conditions of the children" tended to be lower as the disease severity of the child was higher, and there was a significant difference in all parameters between groups 1 and 3 (Table 4).

The percentage of children with functional impairment in daily life was significantly lower in group 1 than in groups 2 and 3 (χ^2: 1 vs 2, $P < .01$; 1 vs 2, $P < .05$). Similarly, the "likelihood of persistent functional impairment in daily life" was significantly lower in group 1 than in groups 2 and 3 (Mann-Whitney: 1 vs 2, $P < .01$; 1 vs 3, $P < .01$). They were both highest in group 2, but there were no significant differences as compared with group 3 (Table 5).

In terms of the subjects beyond the clinically useful cutoff values in the questionnaires, the percentage of those who showed serious anxiety by STAI (51 points or higher by STAI-I and 55 points or higher by STAI-II in females) tended to be higher as the grade of disease severity was higher, and there was a significant difference between groups 1 and 3. However, only the percentage of the subjects beyond the cutoff value of the IES-R-J (25 points or higher) had no correlation with disease severity (Table 6).

Table 5 Functional impairment in daily life

	The number and ratio of children with functional impairment in daily life	Likelihood of persistent functional impairment in daily life
Total (n = 145)	35 (24%)	0.43 (±0.87)
Group 1 (n = 44)	4 (9%)	0.07 (±0.26)
Group 2 (n = 29)	11 (38%)	0.76 (±1.06)
Group 3 (n = 72)	20 (28%)	0.52 (±0.97)
	1-2 ($P < .01$), 1-3 ($P < .05$) (χ^2 test)	1-2 ($P < .01$), 1-3 ($P < .01$) (Mann-Whitney)

There were 29 mothers (20%) with an IES-R-J score beyond the cutoff value, and the breakdown was 8 (18%) in group 1, 2 (7%) in group 2, and 19 (26%) in group 3. The percentage in group 2 was significantly lower than in group 3 (χ^2, $P < .05$) and was lower than in group 1 despite no significant difference. There was no significant difference between groups 1 and 3.

5. Discussion

5.1. Validity of PTSD research in the field of pediatric surgery

To the best of our knowledge, this is the first survey to investigate a variety of diseases in the field of pediatric surgery and PTSD symptoms in mothers of the children after surgery. Therefore, the IES-R-J scores of the mothers cannot be compared with those obtained in other studies in the field of pediatric surgery.

As a representative study on PTSD using the IES-R-J, there has been a report on sexual abuse on females. This survey carried out by Ishii et al [21] in Japan showed that the average score in 225 females aged in their twenties to fifties that had some kind of sexual abuse was 15.9 ± 15.7, as compared with 10.8 ± 14.8 in those who never had such abuse.

Table 6 The subjects beyond the clinically useful cutoff values in the questionnaires

	Number and ratio of mothers		
	Beyond the cutoff value of the IES-R-J	Showed serious anxiety by STAI-I	Showed serious anxiety by STAI-II
Total (n = 145)	29 (20%)	37 (26%)	33 (23%)
Group 1 (n = 44)	8 (18%)	6 (14%)	5 (11%)
Group 2 (n = 29)	2 (7%)	7 (24%)	8 (28%)
Group 3 (n = 72)	19 (26%)	24 (33%)	20 (28%)
χ^2 test	2-3 ($P < .05$)	1-3 ($P < .05$)	1-3 ($P < .05$)

Table 7 Comparison among different supporter groups

Supporter	The IES-R-J score (±SD)	Number and ratio of mothers beyond the IES-R-J cutoff value
Group not including the husband (n = 55)	21.13 (±18.44)	17 (30.9%)
Group including the husband (n = 90)	12.27 (±10.80)	11 (12.2%)
	$P < .01$ (Mann-Whitney)	$P < .01$ (χ^2 test)

Our results indicated that the average IES-R-J score in mothers of children who had undergone surgery was 15.62 ± 14.9 and thus comparable to the score in females who had some kind of sexual abuse. A large-scale study using IES-R in the United States showed that PTSD occurs in 7.8% (5% in males and 10% in females) of the general population at some point during their lifetime [22,23], whereas a survey on pediatric cancer revealed that about 20% to 30% of mothers showed PTSD symptoms [11]. Our results showed that mothers with a score beyond the cutoff value accounted for 20%, which is comparable to the score in mothers of children who survived cancer. These results suggest the validity of using the PTSD model to evaluate psychological status in mothers of children after surgery in the field of pediatric surgery.

5.2. Comparison with previous studies

STAI-I, STAI-II, "current condition of the child," "likelihood of future operations," and "distance from the supporter" strongly correlated with IES-R-J scores in the present study. A strong correlation of IES-R-J scores with STAI-I and STAI-II has been suggested in studies in pediatric cancer [7,8]. The observation that "likelihood of future operations" and "current condition of the affected child" correlated with IES-R-J scores is consistent with a study by Landolt et al [24], who reported that unfavorable clinical courses become a traumatic experience, and the correlation between IES-R-J scores and "distance from the supporter" is consistent with previous reports that self-assessment of support is related to PTSD [8,25].

The results in the present study correspond well to those in previous studies on PTSD in mothers of children who survived serious disease, which indicates that mothers are psychologically affected in the field of pediatric surgery.

5.3. Impact of the fathers

When the impact of the fathers on PTSD in the mothers was considered, the IES-R-J score was significantly lower in the group in which fathers were included in the supporters of the mothers than in the other group, and the number of mothers with scores exceeding the cutoff value was smaller (Table 7).

These results implicate a great impact of the fathers on the psychology of the mothers of the affected children. Therefore, it is expected that pediatric surgeons would try to make efforts to have the father become the primary supporter of the mother as much as possible in families in which he may provide support and would deal with the situation more cautiously in families lacking such support.

Because the "distance from the supporter" correlated with the IES-R-J score, when family members other than the father are present as supporters, it is desirable to ask for their support. In fact, in the field of childhood cancer, there have been intervention studies that examined the fulfillment of family function on a trial basis, and it is thought to beneficial [25].

On the other hand, when fathers cannot become the supporters because of divorce or other reasons, and when it is difficult to expect support from other family members, psychological problems of the mothers become more severe and it becomes difficult to intervene as described. In such cases, pediatric surgeons play critical roles for the mothers.

Previous studies have suggested that it is the mothers who are most strongly influenced by the disease in the affected children [11,12], especially in mothers of children with congenital disease whose operations are carried out during infancy. Therefore, it would be important to make efforts to eliminate anxiety in the mothers whether or not support from the father and other family members is expected.

By not only patiently responding to and supporting the mothers who repeatedly express anxiety and ask questions, but also kindly asking the mothers whether they have anxiety or questions when they do not volunteer them, and respecting the efforts of the mothers, supporters can instill secure feelings in the mothers and strengthen the awareness that they are participating in the treatment of the children.

Pediatric surgeons who are unable to cope with mothers who have severe psychological and psychiatric problems should be made aware of the results of this study so that they understand that such problems are often observed in the mothers and consult specialists quickly.

5.4. Characteristics of PTSD in mothers of children who have undergone surgery for congenital disease

Classification into 3 groups according to disease severity of the child showed that IES-R-J scores tended to be higher as the grade of disease severity was higher (Table 4), and the percentage of subjects with scores higher than the cutoff value was lowest in group 2 (Table 5). This observation is probably because some factors in group 2 suppressed a marked increase in IES-R-J scores.

Almost all of the children categorized into group 2 had anal atresia or Hirschsprung disease and tended to have

higher scores for "functional impairment in daily life" and for "likelihood for persistent functional impairment in daily life," although there was no significant difference, which suggests the importance of paying attention to daily care at home, such as dietary control and bougienage training, for recovery of anal functions.

Therefore, care by the mothers greatly affects the quality of life of the children in this group, and the mothers might improve self-efficacy by confirmation and appraisal of their care at home by physicians at each visit to the clinic.

Today, mothers can rarely become involved in treatment of the symptoms of children in groups 1 and 3, and treatment must be left for physicians.

Best et al [26] implied in their study that an improvement in mothers' self-efficacy attenuates PTSD symptoms. It is possible that the effect of self-efficacy might be confirmed not only in group 2 but also in group 3 with the severest disease.

6. Conclusion

Moderate to severe PTSD was observed in 20% of mothers of children who had undergone surgery for congenital disease at the pediatric surgery department. It would be considered useful to use the PTSD model in dealing with psychological problems in such mothers. Here, PTSD in the mothers correlated with anxiety, "current condition of the child," "likelihood of future operations," and "distance from the supporter." Categorization of the children into 3 groups according to their disease severity revealed that IES-R-J and STAI scores tended to be higher in the group with a higher grade of disease severity, whereas the percentage of mothers with an IES-R-J score beyond the cutoff value was lowest in group 2 with moderate disease severity and had no correlation with the grade of disease severity.

In group 2, the mothers provided some care to their affected children, which seemed to suppress a marked increase in the IES-R-J scores. These results suggest that, in the treatment of disease in the field of pediatric surgery, participation of mothers in the treatment could potentially attenuate PTSD symptoms in mothers.

6.1. Limitation

The number of subjects greatly differed among the groups and was markedly small in the group 2. Because the response rate was more than 50%, this survey was thought to be reliable, but it is necessary to repeat the survey. Moreover, only a mailing survey was carried out, and its combination with an interview survey would provide results that reflect the status more accurately.

Nevertheless, the specificity of IES-R-J after a long-term follow-up was reported to be 71% and relatively high at the time of the survey [17]. In addition, as compared with surveys on the relationship between scores by questionnaires examined by similar methods and surveys including an interview, a number of consistent aspects have been shown in the present study.

Therefore, it is concluded that the overall tendency has been accurately evaluated by the present study.

Appendix A. Other factors in the questionnaire

1. Age of the child at the time of the first explanation of the disease and current age
2. Number of past operations on the child and date of the last operation
3. Degree of the mother's subjective understanding of the child's disease: 4-grade evaluation
4. Degree of the mother's subjective understanding of the child's operation: 4-grade evaluation
5. Disease of the child
6. Degree of the mother's subjective understanding of severity of the child's disease: 4-grade evaluation
7. Current condition of the child: 4-grade evaluation
8. Frequency of the appearance of disease in the child: 4-grade evaluation
9. Likelihood of future operations: 4-grade evaluation
10. Functional impairment in daily life: present or absent
11. Likelihood of persistent functional impairment: 4-grade evaluation
12. Likelihood of relapse and complications after radical surgery: 4-grade evaluation
13. Satisfaction for the physician's explanation of relapse and complications: 4-grade evaluation
14. Distance from the supporter: 4-grade evaluation ("Distance from the supporter" was defined as follows: when the primary supporters for a mother were her husband or her family members including her husband, 1; family members excluding her husband, 2; somebody other than the family members, 3; and no supporter, 4.)
15. Free comment (describe if any)

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