



Should parents share medical information with their young children? A prospective study



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ARTICLE INFO

Keywords:

Pediatric Medical Traumatic Stress (PMTS)

PTSD

Medical information

Surgical procedures

ABSTRACT

Background: As psychiatric consultants to pediatric wards, we are often asked whether to disclose to young children full information about the invasive medical procedures they face. To date, no studies have been published offering an evidence-based answer to this question. This prospective study examined whether sharing medical information with young children regarding invasive interventions correlates with the development of chronic post-traumatic stress three to five months after hospitalization.

Method: The participants in this prospective study were parents of 151 children aged 3–13 who were hospitalized in a pediatric surgery ward. The sample was representative of the population hospitalized in this ward during that year. Independent of the study, parents of 104 children chose to share with them information regarding the procedure they were about to undergo, while parents of 47 children chose not to do so. *t*-Tests were used to assess the correlation between the children's exposure to medical information and their level of long-term post-intervention stress.

Results: Findings show an inverse correlation between the children's exposure to medical information and their level of post-traumatic stress several months after their medical episode. The correlation is significant in both preschool children and school-aged children.

Conclusions: We suggest the implementation of psychoeducation programs among both medical staff and parents in order to increase awareness of the importance of sharing medical information with young children facing medical challenges.

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1. Introduction

1.1. Invasive interventions and the development of pediatric post-traumatic symptoms

Illness and hospitalization requiring surgical interventions are accompanied by pain, fear, uncertainty, helplessness, or even life-threatening situations [1], which may lead to psychological distress and to a significant impairment in the child's functioning, evident, for example, in behavioral problems and decreased academic performance

[2]. Children may come to fear medical devices necessary for their treatment, and be apprehensive about the loss of control entailed by the surgical intervention, the absence of their parents or family, the new surroundings of the hospital ward, or such consequences of the intervention as pain and the appearance of the wounded area [3]. The children's psychological distress is expressed in reaction patterns such as hyperarousal, reliving the experience, and avoidance behaviors [2,4,5]. While most children will recover spontaneously from these reactions after a few weeks, returning to their previous level of functioning without further psychological intervention and leaving no chronic psychological symptoms, 16%–28% of the children exposed to invasive medical procedures, such as surgery, may develop post-traumatic stress symptoms that significantly affect both their physical recovery and their functioning in all areas of life [6].

The current study aims to assess whether exposing young children to information about their medical condition prior to a surgical procedure may help prevent or alleviate long-term post-intervention stress.

Funding source: This manuscript has no external funding.

Financial disclosure: The authors have no financial relationships relevant to this article to disclose.

Potential conflicts of interest: The authors have no conflicts of interest relevant to this article to disclose.

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1.2. The impact of exposing children to information about their medical condition on their level of psychological distress

Some parents avoid exposing their young children to information about their medical condition and conceal information about the impending procedures. Concealment of information by parents is often done with the intention of protecting the child, out of fear that the child would not be able to handle the information [7,8]. Parents may also face difficulties in openly addressing the death-related anxieties of their children due to their own death-related anxieties [9]. Withholding information from children may result in a significant negative psychological toll. Bergman and Cohen [7] note that most children absorb more from their surroundings than their parents realize and believe that important information is kept hidden from them. Furthermore, children's tendency for egocentrism may lead them to assign the cause of external events to themselves. This may engender feelings of guilt and confusion, which, in turn, may lead to withdrawal and depression [7].

Research investigating the psychological impact of pediatric patients' exposure to information about their medical condition has been conducted only on two populations: children diagnosed with HIV and children suffering from cancer [e.g. 10–14]. These studies, conducted among children aged 6–14, compared children whose parents informed them about their diagnosis and its consequences (according to their developmental level), to children from whom this information was withheld. It was found that the reported levels of distress and depression among members of the first group were lower and their level of psychological wellbeing was higher than the children of the second group [10–14].

With respect to invasive interventions, the few published studies have only measured distress prior to surgery [15,16]. Furthermore, these studies addressed only school-aged children. The goal of these studies was to estimate the immediate impact of psychological programs aimed at preparing children aged 8–12, who were scheduled for circumcision or herniorrhaphy [15], on their fears and worries before surgery. The authors found that the pre-surgical preparation, comprising an explanation by an allied health professional and an interactive, multimedia game, reduced the preoperative rate of fear (from 30% to 10%) as well as hyperarousal (from 41.1% to 17.8%) among participants [16]. Neither study addressed the children's long-term post-surgical reactions, and the literature review we performed did not discover studies that do so.

Teaching children about various difficult situations they may encounter, such as hospitalization, may help them to better process such events when they occur [17]. Children relate to information about their illness and prognosis as empowering, conferring strength in handling and treating the illness. Information helps children to adjust their expectations whereas an uncertain future engenders significant fears and worries [18]. Nevertheless, studies show that many parents (as well as some medical professionals) believe that it is unnecessary to explain the situation to young children and consequently do not prepare preschoolers before medical procedures [17]. To combat this phenomenon and increase awareness, evidence is required to determine the extent of the relationship between the concealment of medical information and the development of mental distress even among children aged 3–6. Such data is currently absent from existing literature. Specifically, it is important to assess the impact of exposure to such information as a factor in the development of post-traumatic distress. The purpose of the present study is to provide evidence that will help fill this gap.

2. Method

2.1. Study design

This prospective study comprised two assessments: the first during the child's hospitalization and before the surgical intervention, and the second 3–5 months after hospitalization. It compared parents who shared

full information with their children regarding the surgical procedure and its consequences, to those who did not share this information with their children or revealed it only partially.

2.2. Participants

Hebrew-speaking parents of all children aged 3–13 admitted between March and August 2016 to the Pediatric Surgery ward of Hadassah Ein Kerem Medical Center in Jerusalem, Israel, were invited to participate in the study. Parents of 151 children voluntarily agreed to participate and were admitted to the study; 22 parents (14.6%) declined to participate. Demographic and hospitalization data (sex ratio, reason of admission, length of hospitalization) of the sample group are similar to those of the overall Hebrew-speaking population of this age group hospitalized in the ward ($n = 5164$) during the whole of 2016. Consequently, the research sample is representative. Average parental age was $M = 33.9$ (range 22–60). The study group was divided according to age groups: 67 children aged 3–5 years and 84 children aged 6–13 years. Ninety-one children (61.6%) underwent the preoperative preparation program of the Medical Center, which comprised watching an interactive video and receiving an explanation about the procedure by an allied health professional. Nine parents (5.96%) did not continue to the second assessment of the study. We excluded from the study unconscious children, children who experienced head injury that damaged their brain tissue, and children under the age of three.

2.3. Instruments

Since many of the children in the study sample were too young to be interviewed directly, we opted to use instruments based on parental reports aimed at measuring symptoms of psychological distress in the children. Parents' assessment of their child's post-traumatic symptoms has been highly correlated with the children's self-reports [19]. Nevertheless, to increase validity through triangulation, symptoms of distress were assessed by several instruments.

2.3.1. Semi-structured interview

Following obtainment of informed consent, an experienced clinician (A.B.) conducted a semi-structured interview with the parent. In addition to basic demographic data, the parent was asked whether the child was fully aware of the significance of his or her injury or illness. At the time of this study, the standard practice in this pediatric surgery ward was that physicians inform the parents of the medical condition of their child, and it was up to the parents to decide what information to share with the child and whether to do so directly or through a special preparatory program led by a staff member. During the interview, the clinician checked to what extent the parents had shared the medical information with their child. It was made clear to parents that "full awareness" comprises knowledge (according to the child's age and developmental level) of three issues: the diagnosis, the medical procedure the child is about to undergo, and its consequences. The interviewer rated the answer as "yes" when the parent reported that the child was fully aware and as "no" in all other cases.

2.3.2. CBCL (child behavior checklist)

This instrument is often used in research to assess emotional and behavioral problems of children aged 1.5–18 [20]. In the current study, the two parental versions of the questionnaire were used according to the child's age (1–5 or 6–18). Addressing eight sub-scales (anxiety and depression, withdrawal, somatic complaints, attention problems, thought problems, social problems, rule-breaking behavior, and aggressive behavior), the questionnaire comprises 112–138 items (according to the version) recorded on a 3-point Likert scale (0 = Not true, 1 = Somewhat or sometimes true, 2 = Very true or often true) [20]. The parents were asked to complete this questionnaire twice, once at each assessment of the study. The questionnaire was translated to Hebrew and validated [21].

2.3.3. PTSDSSI (post-traumatic stress disorder semi-structured interview)

This parental-report questionnaire aims to assess symptoms of post-traumatic stress disorder (PTSD) among children aged 1–6. The 29 items of the instrument are recorded on a 3-point Likert scale of agreement (0 = No, 1 = Sometimes, 2 = Yes), addressing the child's reaction during and after an event as well as developmental changes. The Hebrew version of this instrument [22] was used in the current study. Internal validity was established at 0.87 [23].

2.3.4. PCASS (the preschool children's assessment of stress scale)

This parental-report questionnaire aims to assess symptoms of PTSD among children aged 1–6 [24]. The 29 items of the instrument are recorded on a 5-point Likert scale of agreement (1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Frequently, 5 = Always), addressing symptoms of anxiety, fear, sleep problems, mood swings, and developmental withdrawal. Internal validity was established at 0.89.

2.3.5. UCLA-PTSD (the University of California at Los Angeles post-traumatic stress disorder) reaction index: DSM-V version

This widely used questionnaire aims to assess symptoms of PTSD among children aged 6–18. The 31 items of the parental version of this instrument are recorded on a 5-point Likert scale (0 = Not at all, 1 = To a small degree, 2 = To some degree, 3 = To a great degree, 4 = Mostly, 5 = I don't know) representing the frequency of appearance of symptoms. Since it is based on the new DSM version, information regarding the validity and reliability of this instrument is still being gathered [25]. Internal reliability in the current study amounted to 0.98.

2.3.6. SCARED (the screen for child anxiety related emotional disorders)

This widely used questionnaire aims to assess symptoms of anxiety among children aged 6–18. The 41 items of the parental version of the instrument are recorded on a 3-point Likert scale of agreement (0 = Rarely true, 1 = Occasionally true, 2 = Frequently true), addressing five aspects: panic, general anxiety, separation anxiety, social anxiety, and school anxiety. Internal validity was established at 0.83 [26].

2.4. Procedure

The study was approved by the Institutional Review Board of the Medical Center. This prospective study comprised two assessments. During the hospitalization of the child, parents who agreed to participate and signed an informed consent form responded to the semi-structured interview and completed the CBCL questionnaire. The second assessment consisted of a telephone conversation, 3–5 months after the hospitalization, with the same parent who was contacted during the first assessment. The parents were asked to complete the CBCL questionnaire again and two additional questionnaires, according to their child's age group. Parents of children younger than 6 were asked to complete the PTSDSSI and PCASS questionnaires, while parents of children aged 6–13 were asked to complete the UCLA-PTSD-P and SCARED questionnaires. Participants were divided into two groups based on the parents' reports as to the child's full awareness of their medical condition (as mentioned in Section 2.3.1). The statistical analyses aimed to compare these two groups. Given the developmental differences between preschoolers and school-aged children, an independent-samples *t*-test was conducted on the two age groups in this study: 3–5, 6–13. While conducting these tests, we ignored missing data. Subgroup comparison was done through a one-way ANOVA. Effect size was measured using Cohen's *d* scale. The significance level was $\alpha = 0.05$. We used SPSS software to perform all statistical calculations, and calculated the desired sample size using G*Power 3.1.7 software. We calculated the size of the sample according to a 5% level of significance and a test's power of 80%, using a correlation procedure between two variables. There were two potential sources of bias, acquiescence bias and social desirability bias. In order to cope with acquiescence bias, we used questionnaires that allow to replace questions implying that there is a right answer with those that focus on the

respondent's true point of view. In order to cope with social desirability bias, participants were told that the objective of the study was to examine risk factors for the development of Pediatric Medical Traumatic Stress (PMTS), without any specific reference to the hypothesis about the child's level of exposure to medical information.

3. Findings

The study sample consisted of 151 children (68.6% boys) aged 3–13 years, the average being 5.27 ($\sigma = 1.9$). The surgical procedures experienced were in urology (35%), orthopedics (13%), ENT (9%), dermatology (9%), gastroenterology (9%), nephrology (9%), neurology (4%), cardiology (4%), ophthalmology (2%), combined (4%), and other (5%). The period of hospitalization ranged from a few hours to 90 days, averaging 4.5 days ($\sigma = 10.4$). For 75.6% the hospitalization was elective.

In order to assess the participants' baseline, preoperative level of distress, we compared the scores of the first assessment of the CBCL questionnaire of the different study groups. Table 1 shows a paired-sample *t*-test assessing the difference between the first and second assessment of the CBCL questionnaire. The differences between the scores were not statistically significant and all the scores were below the abnormal range.

We compared the children's levels of distress (as measured by the CBCL questionnaire) in the first assessment (time 1) to those measured in the second assessment (time 2). We found that the difference between the two assessments was significant among children who had not been exposed to full medical information (in both age groups). Among children who were exposed to full medical information, the difference was non-significant among children aged 3–5. The difference was significant among children aged 6–13, though the increase was considerably lower than children of the same age group who were not informed about their surgery (a difference of about 5% as opposed to 16% between the groups).

Table 2 shows average, standard deviation, and *t*-test results for each age group.

Results show that among children aged 3–5 whose parents opted not to share with them full information about their medical condition, average post-traumatic stress was significantly higher than in children of the same age group whose parents had shared this information with them. This is true for both the PTSDSSI and PCASS instruments, and further supported by the CBCL scores, which do not specifically measure post-traumatic stress but rather offer a general evaluation of the children's emotional and behavioral problems.

Results are similar for children in the older age group in all three instruments: UCLA-PTSD, CBCL, and SCARED. The latter instrument does not specifically score post-traumatic stress but rather offers an evaluation of anxiety symptoms.

4. Discussion

This is the first prospective study to document data on the association between exposing preschoolers to information about invasive procedures that they are about to experience and the development of chronic post-traumatic distress. The results show that children who had not been exposed to full information about their medical condition exhibited higher levels of chronic post-traumatic distress, and that this correlation is as significant in preschool children as it is in school-aged children.

These findings are in line with studies showing similar results for school-aged children diagnosed with HIV or cancer. Instone [10] reported that children who were not told about their HIV-carrier status expressed, both in drawings and communication with their parents, more psychological distress, low self-esteem, and social isolation compared to children who were told about their condition. Among children aged 6–11 who were carriers of HIV, the children's awareness of their

Table 1

A paired-sample *t*-test assessing the difference between the first and second assessment of the CBCL questionnaire.

	Time 1 Before surgery			Time 2 After surgery			t (comparing the 2 times)	df
	N ^a	M	SD	N ^a	M	SD		
	Age group 3–5 years							
Children unaware of their medical condition	26	7.40	2.12	26	30.62	18.27	11.52**	25
Children aware of their medical condition	41	4.88	1.92	41	5.17	7.63	0.77	40
t (comparing the 2 groups)		1.21			7.92**			
df		70			65			
Age group 6–13 years								
Children unaware of their medical condition	21	19.14	7.29	21	35.52	17.72	7.62*	20
Children aware of their medical condition	63	7.33	3.25	63	12.27	4.58	0.95*	62
t (comparing the 2 groups)		1.95			5.22**			
df		86			82			

* *p* < 0.05.

** *p* < 0.01.

^a Differences in N due to missing values.

condition was found to be a significant factor accounting for variance in their level of depression and general anxiety: children with higher awareness had lower levels of anxiety and depression [11]. Similarly, children aged 6–16, who were carriers of HIV but were not told about their status, were found to report higher levels of psychological distress than children who knew about their status [27]. Following similar findings, the American Academy of Pediatrics (AAP) issued guidelines for parents whose children are HIV carriers, advocating informing the children about their status. These guidelines state that children and adolescents who are aware of their status and its progression exhibit higher self-esteem and are at a lower risk of depression compared to children who are not told about their status [28].

Findings among school-aged children with cancer show similar results. Among children aged 8–16 diagnosed with cancer, a negative relationship was found between the extent to which parents shared information with the children regarding their disease and its prognosis, and the children's levels of anxiety and depression [29]. Moreover, even in cases characterized by the worst prognosis (no expected recovery or even imminent death), in as much as parents shared information openly, the child's psychological well-being increased. No equivalent data is available for preschoolers. With respect to pediatric invasive interventions, researchers studied the influence of preoperative preparatory programs on the pre-surgical development of fears and worries [15,16]. They did not examine whether exposing children to information about their medical condition influenced the development of post-traumatic symptoms that persist a few months after the hospitalization.

Our study sought to fill this gap. The results of the *t*-test we conducted to compare the scores of the first assessment and the second assessment by the CBCL questionnaire support our conclusions. The comparison of the

baseline assessment, before the surgical intervention, did not show statistically significant differences. The scores were below the abnormal range, suggesting that there was no difference in the baseline preoperative level of distress among the children of the different groups. In the second assessment, the increase in the level of distress was found to be significant among children whose parents did not share full information with them. This supports our claim that the increase in the level of distress measured in the second assessment is associated with the parents' decision whether to share with their children full medical information. Alternative explanations for the increase in the level of distress, however, cannot be ruled out, since our statistical analyses did not control for various intervening factors.

Despite its limitations, this study is the first to present empirical data pointing to an association between children's awareness of their upcoming medical procedure and their level of distress. Medical staff's awareness of these findings is particularly important, as research shows that only some 10% of physicians believe that children may develop post-traumatic stress and anxiety symptoms following hospitalization. A similarly low percentage of physicians are aware of instruments by which such symptoms may be assessed [30].

The key limitation of this study is that the size of the sample does not allow for an examination of the correlations between other factors and the development of post-hospitalization distress symptoms. Among the confounders that may correlate with the children's levels of distress are the type and severity of the medical procedures, the length of hospitalization, the baseline (pre-hospitalization) factors of the children and their parents (such as the previous pattern of relationship between them), and the degree of risk (including the risk of death). Parental stress, coping, and resilience should be considered as candidate predictors of the child's distress, and the possibility that these factors may affect the parents' decision to share information with their children should be studied as well [see 31–34]. Nevertheless, our findings suggest that steps should be taken to provide parents with support, in order to enable them to disclose information about the diagnosis and medical procedure to their children.

Another limitation is the fact that all the measurements were based on parental reports. It was important to us that the study sample will be representative of the population hospitalized in this pediatric surgery ward, and consequently we included a very wide age range (3–13). We excluded from the study children younger than 3 years because sharing information with pre-verbal children is completely different from doing so with older children. Since many of the children in the study sample were too young to be interviewed, it was not possible to assess directly the children's own knowledge of their condition or their symptoms of distress. Parental assessment of their child's post-traumatic symptoms has been highly correlated with the children's self-reports [19]. Nevertheless, to increase validity, multiple instruments for measuring distress were used in each age group, which indeed reinforce results among the entire study population.

Table 2

Average, standard deviation, and mean differences (*t*-test) for all second-stage questionnaires per age group and child's awareness of their medical condition.

Instrument	Children unaware of their medical condition			Children aware of their medical condition			t	df
	N ^a	M	SD	N ^a	M	SD		
	Age group 3–5 years							
CBCL (time 2) after surgery	26	30.62	18.27	41	5.17	7.63	7.92**	65
PTSDSSI	24	1.32	0.45	24	0.11	0.29	10.17**	46
PCASS	29	45.75	4.77	20	22.21	3.03	21.16**	47
Age group 6–13 years								
CBCL (time 2) after surgery	21	35.52	17.72	63	12.27	4.58	5.22**	82
UCLA-PTSD	21	2.35	0.98	63	1.30	0.45	6.7**	82
SCARED	15	1.07	0.35	42	0.20	0.35	8.28**	55

p* < 0.05 *p* < 0.01.

^a Differences in N due to missing values.

There is no standardized tool for measuring awareness of specific information among children in such a wide age range. Our main focus was not to measure children's awareness but to compare the outcomes (in terms of symptoms of psychological distress) between children whose parents fully shared the medical information with them and children whose parents chose not to do so. Our findings, therefore, clearly do not allow the drawing of a cause-effect relationship between awareness of medical information and post-traumatic distress, and further research is needed in order to evaluate the relative influence of each of the previously mentioned possible confounders. Nevertheless, our results provide some preliminary evidence in order to give a research-informed answer to the question driving our study: should parents fully share medical information with their children?

5. Conclusions

The findings of this study have several clinical applications. First and foremost, they suggest that providing information to preschoolers is just as important as to school-aged children. Second, improving the awareness of parents and staff alike towards the risks of not sharing medical information prior to pediatric invasive interventions and the benefits of sharing such information, could help reduce the development of chronic post-traumatic stress in children. Future research is needed to prospectively study the potential of psychoeducational guidance programs to attenuate the development of post-traumatic symptoms following pediatric hospitalization and invasive interventions as well as to improve the compliance of children of all ages with the medical follow-up. Future research is also needed to examine personal and family-related factors that influence parents' decisions on whether or not to share medical information with their children prior to invasive interventions.

Acknowledgment

We acknowledge the Herman Dana Foundation for its support of this research project.

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