



Paediatric Medical Traumatic Stress in Children with Cancer and their Parents: Difference in Stress Levels Due to Illness and Treatment Factors

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Abstract

Pediatric medical traumatic stress (PMTS) is a set of children's and their parents' psychological and physiological responses to pain, injuries, serious illnesses, and other experiences with the medical environment. Pediatric cancer patients have the highest prevalence of PMTS as the illness its treatment involve a set of stressors that trigger many negative psychological reactions. The current study examined the difference in levels of traumatic stress in children with cancer and their parents due to medical factors (type of cancer, outcome, duration, and intensity of treatment, time since diagnosis, relapse, and hospitalization in ICU). The study involved 183 parents of 133 children and 62 children and adolescents who were treated between 2009 and 2019 at the Clinical Department of Pediatric Hematology and Oncology of University Children's Hospital in Ljubljana. We collected the data using The Intensity of Treatment Rating Scale 2.0 [IRT-2], PTSD Checklist for Children/Parent [PCL-C/PR], The PTSD Checklist for DSM-5 [PCL-5] and The Child PTSD Symptoms Scale for DSM-5 [CPSS-5]. Traumatic stress symptoms are frequently present in both children and their parents, regardless of the cancer type, treatment duration, and treatment outcome. Children with relapse, children with more intensive treatment, and parents of the latter are at higher risk for PMTS occurrence. Additionally, we found a decreasing trend of traumatic responses after five or more years post-cancer diagnosis.

What is Known:

- Paediatric cancer is still perceived as a life-threatening illness that despite the advance in medical science is still often accompanied by painful and consequently traumatic medical procedures.
- Stress and uncertainty due to cancer and its treatment can lead to traumatic experiences in both, children and parents.

What is New:

- Children with relapse, children with more intensive treatment, and parents of the latter are at higher risk for paediatric medical traumatic stress occurrence.
- Despite the fact of declining trend of traumatic responses after more than five years since diagnosis, psychological interventions are needed in both, during and after the treatment.

Keywords Children · Neoplasms · Oncology · Parents · Pediatric medical traumatic stress · Posttraumatic stress symptoms

Abbreviations

ASD	Acute stress disorder
CPSS-5	The Child PTSD Symptoms Scale for DSM-5
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5 th edition
ICU	Intensive Care Unit
IRT-2	The Intensity of Treatment Rating Scale 2.0
<i>IQR</i>	Interquartile Range
<i>M</i>	Mean
<i>Mdn</i>	Median
<i>N</i>	Numerus

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PCL-5	The PTSD Checklist for DSM-5
PCL-C/PR	PTSD Checklist for Children/Parent
PMTS	Paediatric medical traumatic stress
PTSS	Post-traumatic stress symptoms
PTSD	Post-traumatic stress disorder
SD	Standard Deviation

Introduction

In children and adolescents cancer is a rare illness. In Slovenia, approximately 74 (0.009% of population of children and adolescents in Slovenia) children under the age of 20 are diagnosed with cancer annually (Zadnik et al., 2020). The incidence of cancer in children and adolescents has been rising over the last decades, while mortality has been declining. Today we cure 80% of children and adolescents with cancer (Zadravec Zaletel, 2009).

With the advancement in medical science, survival rates for many forms of pediatric illnesses and injuries have increased over the last 40 years (Friedman & Meadows, 2002). Consequently, other health effects that go beyond the illness become more noticeable. These effects include illness-related and treatment-related psychological consequences. Events related to acute medical conditions, chronic illnesses, injuries, necessary medical interventions and various forms of invasive treatment represent one of the most common traumatic situations in childhood (Pai & Kazak, 2006).

Pediatric Medical Traumatic Stress

PMTS (pediatric medical traumatic stress) is a set of psychological and physiological responses of children and their families to pain, injuries, serious illnesses, medical procedures, and intensive or intimidating treatment experiences (National Child Traumatic Stress Network, 2003). PMTS includes traumatic stress responses, such as arousal, re-experiencing and avoidance, which can vary in intensity and can interfere with an individual's functioning. It is an acute stress reaction to medical procedures or other experiences related to treatment and medical environment. It can occur in response to a single or multiple medical events.

PMTS is associated, but not limited to ASD (acute stress disorder) or PTSD (post-traumatic stress disorder), as the specific conditions of those diagnoses are not entirely consistent with the phenomenology of children's and parents' responses to medical events. Therefore, PMTS is not defined as PTSD but as PTSS (post-traumatic stress symptoms), which represent a continuum of key symptoms of PTSD (arousal, re-experiencing and avoidance). Those symptoms may be present without an individual meeting the full diagnostic criteria for ASD or PTSD (Kazak et al., 2006).

Most children and their families competently and flexibly adapt and cope with the illness and the situation (Kazak et al., 2007). However, some families do not adapt to the situation as expected. In those cases, responses to an extremely severe, life-threatening event manifests as excessive arousal, re-experiencing and avoidance.

According to The National Child Traumatic Stress Network (2003) up to 80% of children and their families experience mild forms of traumatic stress due to experiences of a severe, life-threatening illness, injuries or painful medical procedures. 20–30% of parents and 15–25% of children experience permanent traumatic stress, which can interfere with daily functioning and affects the course of treatment and recovery. In Slovenia 76.5% of adults (age 18 to 75 years) reported at least one ACE (adverse childhood experience), and 27.2% reported four or more ACEs (Kuhar & Zager Kocjan, 2022). In population of children with cancer and their parents in Slovenia around 15% of children and 17% of parents experience clinically relevant PMTS (Klašnja, 2020). Subclinical and clinical PMTS have a significant impact on physical health outcomes in families facing pediatric illness or injury (Price et al., 2015).

PMTS in Pediatric Oncology Patients

Cancer and its treatment involve a number of stressors that trigger many negative psychological reactions (Kangas et al., 2002). Traumatic stress symptoms are one of the most common psychopathologies in oncology patients (Cordova et al., 2017; Kanges et al., 2002).

A review of studies published between 1994 and 2004 that examined cancer-related traumatic stress symptoms in pediatric oncology patients and their parents found a high prevalence (Bruce, 2006). According to recent research, PMTS is present in 8–75% of children who have had cancer and in 20–22% of their parents. A similar proportion of children and parents report high levels of persistent distress, which has a disruptive effect on the fulfilment of family, work, medical and treatment demands (Ingerski et al., 2010).

Pediatric oncology patients receive highly invasive, intensive and long-term treatment, possibly accompanied by complications that can additionally endanger a child's life. Children involved in active treatment are more susceptible to various bacterial, viral and fungal infections. In transplantation, one of the possible complications is graft versus host disease (GVHD). Additionally, there is a possibility of a recurrence of the illness (relapse). The aforementioned complications prolong children's hospitalization and treatment, which contribute to an increased risk of manifestation of traumatic stress symptoms and PMTS (Dunn et al., 2012; Rennick et al., 2002).

Dunn and colleagues (2012) found that there are differences in levels of traumatic stress between the group of

parents of children who were diagnosed with cancer for the first time and the group of parents of children who had a recurrence of cancer. Mothers experience comparable rates of traumatic stress, while fathers experience it in greater extent if their child is treated for relapse.

One of the complications of treatment is also hospitalization in intensive care unit (ICU). Negative psychological consequences that ICU can have on children and parents might occur up to one year after discharge (Rennick & Rashotte, 2009). Younger, more severely ill children who undergo a number of invasive medical procedures are at greater risk of developing a variety of negative psychological consequences, such as PMTS (Rennick et al., 2002).

Pediatric cancer is still perceived as a life-threatening illness that despite the advance in medical science is still often accompanied by painful and consequently traumatic medical procedures (Stuber et al., 1996). Stress and uncertainty due to cancer and its treatment can lead to traumatic experiences in both, children and parents (Landolt et al., 2003).

The purpose of the current study was to examine PTSS in children with cancer and their parents due to coping with a serious illness and treatment complications. We were interested in whether there were differences in levels of PTSS in children with cancer and their parents according to illness and treatment factors, such as cancer type, treatment outcome, duration of treatment, time since diagnosis, intensity of treatment, recurrence of illness and hospitalization in ICU.

Method

Participants

The study was conducted between July 2019 and January 2020 at University Children's Hospital of Ljubljana, Department for Pediatric Hematology and Oncology. Of the invited parents of 705 children, parents of 18.7% of children participated. Of the invited, 183 parents (121 mothers and 62 fathers, mean age 40.8) of 133 children (67 females and 66 males, mean age 10.3) who were treated for different type of cancer at our unit since 2009 participated in the study. During the study, 55 children were included in active treatment, 74 had already completed active treatment and 4 had a treatment-resisted illness. In addition, 62 children participated independently (31 females and 31 males, mean age 15.3). Parents and their children who have been treated for less than a month or had died from the illness or its consequences were not included in the study. Other sample characteristics are presented in Tables 1, 2.

Table 1 Demographic and illness variables of the included children

Variable	<i>N</i> = 133 ^a	<i>N</i> = 62 ^b
Gender, <i>n</i> (%)		
Boys	66 (49.6)	31 (50.0)*
Girls	67 (50.4)	31 (50.0)*
Current age, <i>M</i> ± <i>SD</i> (years)	10.3 ± 6.2	15.3 ± 3.9*
Age at diagnosis, <i>M</i> ± <i>SD</i> (years)	7.6 ± 5.6	12.2 ± 4.6*
Diagnosis, <i>n</i> (%)		
Blood cancer	74 (55.6)	41 (66.1)*
Brain tumors	19 (14.3)	5 (8.1)*
Solid tumors	22 (16.5)	11 (17.7)*
Other	18 (13.5)	5 (8.1)*
Years since diagnosis, <i>Mdn</i> (<i>Q</i> ₃ – <i>Q</i> ₁)	2 (4 – 0)	2 (4 – 1)*
Treatment duration, <i>M</i> ± <i>SD</i> (month)	8.7 ± 4.7	9.1 ± 4.6*
IRT-2, <i>n</i> (%)		
Level 1–2	66 (49.6)	23 (37.1)*
Level 3–4	67 (50.4)	39 (62.9)*
Treatment outcome, <i>n</i> (%)		
Active treatment	57 (42.9)	27 (43.5)*
Recovery without severe consequences	66 (49.6)	29 (46.8)*
Recovery with severe consequences	6 (4.5)	4 (6.5)*
Treatment-resistant illness	4 (3.0)	2 (3.2)*
Relapse, <i>n</i> (%)	15 (11.3)	9 (14.5)*
Complications, <i>n</i> (%)	69 (51.9)	27 (51.9) ^c

^acolumn includes children's data reported by parents

^bcolumn includes data of children who participated independently

^cchildren whose parents didn't participate are excluded from the analyses

Assessment

The Intensity of Treatment Rating Scale 2.0 [IRT-2]

The Intensity of Treatment Rating Scale 2.0 was used to determine the treatment intensity of the individual patient. The scale classifies 34 types of cancer and forms of treatment into four levels, from the least intensive to the most intensive treatment (Werba et al., 2007).

Table 2 Demographic variables of the included parents

Variable	<i>N</i> = 183
Gender, <i>n</i> (%)	
Mothers	121 (66.0)
Fathers	62 (34.0)
Age, <i>M</i> ± <i>SD</i> (years)	40.8 ± 6.8
Level of education, <i>n</i> (%)	
High school or less	89 (48.6)
More than high school	94 (51.4)

The PTSD Checklist for DSM-5 [PCL-5]

The checklist consists of 20 items related to the symptoms of PTSD according to the DSM-5 classification system (Weathers et al., 2013). To indicate the extent to which certain symptoms have been present in an individual in the last month we used a 5-point Likert scale (0 – not at all, 1 – a little bit, 2 – moderately, 3 – quite a bit, 4 – extremely). The symptoms are categorized into four subscales – re-experiencing, avoidance, emotional numbness and excessive arousal. In the practice of clinical psychology, the value of 33 points is used as the cut-off score for determining the clinically significant symptoms of PTSD (Blevins et al., 2015).

PTSD Checklist for Children/Parent [PCL-C/PR]

The checklist refers to the child's experience as observed by parents. It consists of 17 items related to the symptoms of PTSD according to the DSM-IV classification system. Parents indicate the extent to which their child has experienced any of the following symptoms of PTSD in the last month, using the 5-point Likert scale (1 – never, 2 – rarely, 3 – sometimes, 4 – often, 5 – very often). The symptoms are categorized into three subscales – re-experiencing, excessive arousal and avoidance and numbness (Ford & Rogers, 1997). In the practice of clinical psychology, the value of 44 points is used as the cut-off score for determining the clinically significant symptoms of PTSD (Ford et al., 1999).

The Child PTSD Symptoms Scale for DSM-5 [CPSS-5]

The scale is intended to assess the presence of PTSD symptoms according to the DSM-5 classification system in children and adolescents exposed to trauma. It is used in children over the age of 8. The scale consists of two parts, the first includes 20 items, which are answered using a 5-point Likert rating scale (0 – not at all, 1 – once a week or less/a little, 2 – 2 to 3 times per week/somewhat, 3 – 4 to 5 times per week/a lot, 5 – 6 or more times a week/almost always). The symptoms are categorized into four subscales – re-experiencing, avoidance, cognitive and mood changes, increased arousal and responsiveness. The second part consists of seven statements, which are answered with YES or NO and are related to areas of functioning in a child's life. In the clinical practice the value of 31 points is used as the cut-off score for determining the clinically significant symptoms of PTSD (Foa et al., 2018).

Procedure

Parents completed The Intensity of Treatment Rating Scale 2.0 (IRT-2), The PTSD Checklist for DSM-5 (PCL-5), PTSD Checklist for Children/Parent (PCL-C/PR) and a demographic questionnaire. Parents completed the questionnaires independently. Children over the age of eight completed The Child PTSD Symptoms Scale for DSM-5 (CPSS-5). Children and parents whom we could not ask in person, were contacted by post. In those cases, the questionnaires were accessed via an application on the internet, where 62 parents (32 mothers and 30 fathers) and 20 children (9 boys and 11 girls) responded to online invitation.

Statistical Analysis

All participants were included in the final data analysis. Data concerning the child and their health condition were in most cases reported by their parents. When the parents of the participating adolescents were not willing to cooperate, data on the health condition were obtained from the medical documentation. Non-parametric tests were used according to the distribution of data.

Results

In 48 cases both parents participated in the study. There were no statistically significant differences in their assessment (PCL-C/PR) of child's experience of PTSS ($T = 328.0$, $Z = -0.87$, $P = 0.221$). The inter-rater reliability is good ($ICC = 0.72$). Also, there were no statistically significant differences comparing child's self-reports (CPSS-5) and parents reports (PCL-C/PR) of their child's experience of PTSS ($T = 1160.5$, $Z = -1.22$, $P = 0.221$). In this case the inter-rater reliability is poor ($ICC = 0.21$).

Type of Cancer

Using the Kruskal-Wallis test we examined the differences in levels of posttraumatic stress symptoms (PTSS) in parents and children with different types of cancer (blood cancer, brain tumors, solid tumors and other forms of cancer). Both, children ($H_{(3)} = 3.61$, $p = 0.307$) and parents ($H_{(3)} = 0.94$, $p = 0.816$) did not experience statistically significant differences in levels of PTSS according to different types of cancer. Additionally, the difference in levels of PTSS is not statistically significant in children who self-reported ($H_{(3)} = 1.45$, $p = 0.695$).

Treatment Outcome

According to treatment outcome (active treatment, treatment without severe consequences, treatment with severe consequences, illness resistant to treatment) we did not find statistically significant differences in experiencing PTSS in both, parents ($H_{(3)} = 4.20$, $p = 0.240$) and children ($H_{(3)} = 7.14$, $p = 0.068$). Additionally, the difference in levels of PTSS is not statistically significant in children who self-reported ($H_{(3)} = 2.62$, $p = 0.240$).

Treatment Duration

According to treatment duration (1–3 months, 3–6 months, 6–12 months and more than 12 months) we did not find statistically significant differences in experiencing PTSS in parents ($H_{(4)} = 2.59$, $p = 0.629$) and children ($H_{(4)} = 4.67$, $p = 0.323$). Additionally, the difference in levels of PTSS is not statistically significant in children who self-reported ($H_{(4)} = 4.46$, $p = 0.347$).

Time Since Diagnosis

According to time since diagnosis (1–6 months, 6–18 months, 18 months–5 years, 5 years or more) we did not find statistically significant differences in experiencing PTSS in children who self-reported of experiencing PTSS ($H_{(3)} = 4.70$, $p = 0.195$) and in children whose parents reported about their experiences ($H_{(3)} = 1.88$, $p = 0.597$). However, parents differ in PTSS experiences according to time since diagnosis. The difference is statistically significant ($H_{(3)} = 7.93$, $p = 0.048$, $e^2 = 0.04$). Parents of children diagnosed one to six months' prior ($Mdn = 20.5$, $IQR = 28.25 - 7.75$) are most likely to experience PTSS, followed by parents of children who have been diagnosed 18 months to five years ago ($Mdn = 15$, $IQR = 32 - 5$). Parents of children who have been diagnosed six to 18 months earlier are less likely to experience PTSS ($Mdn = 10$, $IQR = 20 - 5$), and the parents of children who have been diagnosed more than five years ago are the least likely ($Mdn = 9$, $IQR = 22 - 1$). The post-hoc Mann–Whitney test according to the Bonferroni correction of 0.008 (0.05/6) does not show statistically significant differences in PTSS between different time periods since diagnosis.

Intensity of Treatment

Parents of children who received more intensive treatment ($Mdn = 16$, $IQR = 30.25 - 9$) experience PTSS to greater extent than parents of children who receive less intensive treatment ($Mdn = 11$, $IQR = 23 - 3$). Using the Mann–Whitney test we found that the difference in PTSS experiences was statistically significant ($U = 3388.50$,

$Z = -2.22$, $p = 0.026$, $r = -0.16$, $1 - b = 0.18$). Additionally, we found that according to parents there are statistically significant differences in experiences of PTSS in children who receive different levels of treatment intensity ($U = 3045.00$, $Z = -3.18$, $p = 0.001$, $r = -0.24$, $1 - b = 0.35$). Children who receive more intensive treatment ($Mdn = 29.5$, $IQR = 39.25 - 22.75$) experience PTSS to greater extent than children who receive less intensive treatment ($Mdn = 23$, $IQR = 30 - 19$). In children who self-reported the Mann–Whitney test showed no statistically significant differences in levels of PTSS ($U = 384.0$, $Z = -0.94$, $p = 0.347$) between the group who received less intensive treatment ($Mdn = 7.0$, $IQR = 21.0 - 4.0$) and the group who received more intensive treatment ($Mdn = 14.0$, $IQR = 19.0 - 6.0$).

Recurrence of Illness

Parents report that children with relapse ($Mdn = 33.5$, $IQR = 52.75 - 29.25$) experience PTSS to a greater extent than children who are dealing with cancer for the first time ($Mdn = 25.0$, $IQR = 32.0 - 19.0$). The Mann–Whitney test showed statistically significant differences in experiences of PTSS between the monitored groups of participants ($U = 826.00$, $Z = -3.60$, $p < 0.001$, $r = -0.27$, $1 - b = 0.19$). In children who self-reported experiences of PTSS the Mann–Whitney test showed no statistically significant differences in experiences of PTSS ($U = 196.0$, $Z = -0.85$, $p = 0.395$) between children with relapse ($Mdn = 14.0$, $IQR = 20.0 - 8.5$) and children who are dealing with cancer for the first time ($Mdn = 12.0$, $IQR = 20.0 - 4.0$).

Between the parents of children who are dealing with cancer for the first time ($Mdn = 12$, $IQR = 26 - 4$) and parents of children with relapse ($Mdn = 18$, $IQR = 49.0 - 7.5$) we found that differences in PTSS experiences were not statistically significant ($U = 1221.00$, $Z = -1.83$, $p = 0.068$). We found statistically significant differences ($U = 328.00$, $Z = -2.55$, $p = 0.011$, $r = -0.23$, $1 - b = 0.11$) between mothers of children who were diagnosed with cancer for the first time ($Mdn = 15$, $IQR = 29.75 - 6.00$) and mothers of children with relapse ($Mdn = 46$, $IQR = 85 - 16$). Between fathers of children who were diagnosed with cancer for the first time ($Mdn = 9$, $IQR = 22 - 2$) and fathers of children with relapse ($Mdn = 16$, $IQR = 20.0 - 3.5$) we found that differences in experiences of PTSS are not statistically significant ($U = 206.00$, $Z = -0.49$, $p = 0.626$).

Intensive Care

Between parents of children who were hospitalized in ICU ($Mdn = 15.5$, $IQR = 33 - 4$) and parents of children who were not hospitalized in ICU ($Mdn = 13$, $IQR = 25 - 5 - 4$) we did not find statistically significant differences in experiences of PTSS ($U = 2728.00$, $Z = -0.77$, $p = 0.440$). Additionally,

we did not find statistically significant differences in experiences of PTSS ($U = 2378.50$, $Z = -1.94$, $p = 0.053$) between children hospitalized in ICU ($Mdn = 30$, $IQR = 36-75 - 23$) and children who did not have this experience ($Mdn = 25$, $IQR = 34-5 - 19$). However, there were only 41 parents who have reported having an experience of child being treated in the ICU.

Discussion

In our study we have found that PTSS is present in children and their parents regardless of cancer type. This finding is consistent with some findings of previous research (Bruce, 2006; Phipps et al., 2009). It is difficult to assume that any type of cancer poses a higher risk of manifestation of PTSS compared to other types of cancer since all types of cancer are considered life threatening.

Children from different treatment outcome groups as well as their parents do not differ in the rate of experiencing PTSS. Based on this we can conclude that those involved in active treatment and those who have completed the treatment experience comparable levels of PTSS. Moreover, similar conclusions are reported by Phipps et al. (2009). On the other hand, other researchers found that parents of children with cancer are more likely to experience PTSS if their child is actively treated in comparison to parents of children who have completed the treatment (Okado et al., 2016). It is likely that other factors (fear of illness recurrence, socio economic factors, quality of life etc.) contribute to levels of traumatic stress in children and parents that participated in our study. Further research to assess these factors is needed.

The duration of treatment does not significantly contribute to differences in the rate of PTSS experiences in both children and parents. One of the studies reported that the first six months of treatment pose the highest risk of manifestation of PTSS in mothers of children with leukemia (Tremolada et al., 2013). McCarthy and colleagues (2012) reported about lower levels of PTSS in parents later in treatment. We can assume that families are still in a transition period shortly after a diagnosis and thus fail to establish stable patterns of adaptation to stressful situations. This is why they experience greater levels of PTSS (Okado et al., 2016).

There are no differences in experiences of PTSS in children according to time elapsed since diagnosis, while in parents there is a slight but significant difference in PTSS levels. In conclusion, with time since diagnosis PTSS levels in parents decrease. We found that PTSS are gradually declining after more than five years since beginning of treatment in children's self-reports and parents, which is consistent with some finding of other research (Phipps et al., 2009). According to parents' reports of symptoms in

their children's we do not observe this moderation in levels of PTSS more than five years after diagnosis. As stated in the literature the recently diagnosed patients report higher levels of PTSS than those diagnosed several years prior (Phipps et al., 2005). Our current study sample of children and adolescents revealed a slightly different picture. Children and adolescents do not report having higher levels of PTSS. However, their parents of children who have been diagnosed one to six month prior to our study reported highest PTSS probably due to adaptation process, followed by parents of children who have been diagnosed 18 months to five years ago. The experience of parents after 18 months to five years since beginning of treatment may reflect the influence of other stressors that are not directly related to cancer or its treatment, but to the challenges they deal with after recovery. These challenges are the effects of treatment and include difficulties in reintegration into school and work environment, lifestyle reorganization, potential mental health problems, and other stressful life events (Kahalley et al., 2013).

Factors, such as involvement into active treatment and time elapsed since diagnosis play an important role in levels of PTSS. One of the studies reported a higher incidence of PTSS levels in patients enrolled in active treatment (Pelcovitz et al., 1998) and in those who had recently been diagnosed with cancer (Phipps et al., 2005) compared with patients who completed the treatment years ago. The frequency and the intensity of PTSS decline over time as families adjust to the child's illness and the treatment requirements (Okado et al., 2016). It is important to acknowledge that most families successfully adapt to demands and changes in family roles due to coping with cancer (McCubbin et al., 2002). In conclusion, there is a trend of gradually establishing clearer and more stable patterns of family adjustment.

Children receiving more intensive treatment experience PTSS to a greater extent than children whose treatment is classified as one of the less intensive treatment categories (level 1 or level 2). We came to the same conclusion regarding the parents. According to the findings of previous research the rate of PTSS levels is not significantly related to illness severity and treatment intensity, but with the perceived threat (Barakat et al., 2006; Bruce, 2006). On the other hand, Stubar and colleagues (2010) report that increased risk of manifestation of PTSS is associated with treatment intensity.

Parents reported that children with relapse experience PTSS to a greater extent than children who were diagnosed with cancer for the first time. However, in children's self-reports we discovered comparable levels of PTSS regardless of the presence of relapse. This might be a reflection of a small sample of participants with relapse but also a different interpretation of child's behavior between child and his parent. Previous research on this

area is somewhat inconsistent, reporting no significant differences in PTSS experiences (Okado et al., 2016) and research that reports greater levels of PTSS in patients with relapse (Phipps et al., 2009).

There is no significant difference in PTSS experiences between parents of children who were diagnosed for first time and parents of children with relapse. In conclusion, parents of both groups experience comparable levels of distress due to coping with a child's illness. Our findings are not entirely consistent with previous research that report about higher levels of PTSS in parents of children with relapse compared to parents of children diagnosed for the first time (Jurbergs et al., 2009). Dunn and colleagues (2012) found that mothers experience comparable levels of PTSS regardless of the presence of relapse, while fathers experience greater levels of PTSS in case of relapse. In our current study sample of parents, we found the opposite. Mothers of children with relapse reported higher levels of PTSS in comparison to mothers of children diagnosed for the first time. In fathers this difference was not significant.

In both, parents and children we discovered no significant differences in levels of PTSS according to the presence of hospitalization in the ICU. Our findings are not consistent with existing literature, which reports that there is a significant difference in levels of PTSS between children hospitalized in ICU and children hospitalized only in general departments of the clinic where children hospitalized in ICU experience PTSS to a greater extent. Similar findings are reported in parents when their child was hospitalized in ICU (Rees et al., 2004). Other studies concluded hospitalization in ICU has some impact on the development of PTSD (Connolly et al., 2004). This might also be a reflection of a smaller sample of children who were treated in the ICU and their parents.

The study included a large and fairly heterogeneous sample of participants according to cancer type, but the sample is still in somewhat unbalanced regarding other medical factors, for example relapse, treatment duration, time since diagnosis, treatment outcome, hospitalization in ICU. In addition, the sample of parents has an unbalanced sex ratio. Sample characteristics might have influenced the results. Another limitation of our study is not assessing the impact of psychological interventions, which certainly have an effect on rates of traumatic stress.

Further research could focus on discovering which type of psychological intervention has an impact on decreasing rates of traumatic stress in pediatric cancer patients and their caregivers. In order to identify the possible causal effects of time on the intensity of PTSS a longitudinal research approach would be necessary as it would allow us to identify families at higher risk for long-term maladaptation.

Conclusion

Due to cancer, its treatment and possible complications PMTS is largely present in both children and parents in our study regardless of cancer type, treatment duration and treatment outcome. Children with relapse, children with more intensive treatment, and parents of the latter are at higher risk for PMTS occurrence. Despite the fact that traumatic responses gradually decline after more than five years since diagnosis, psychological interventions are needed in both, during and after the treatment (Kazak et al., 1997). In addition, it is important to monitor recovered children and their parents for years after treatment. Children and parents may be exposed to the effects of other stressors that are not directly related to the illness or its treatment, but to the challenges they face after recovery.

In recent years there has been a growing interest and an awareness of the importance of early identification of PMTS and preventing re-traumatization and its negative consequences. These insights are actively integrated into the health system and their work policies in the context of trauma-informed care. Furthermore, it would be reasonable to start systematically introducing measures to prevent PMTS in Slovenia. At the Department of pediatric hematology and oncology we strive to reduce traumatic stress responses through psychological interventions, which include psychoeducation for all parents, identifying vulnerable families and offering psychological support to children as well as parents. At the department we use team approach, where psychologist and medical staff work closely together in treating children and communicating with parents. We also use measures to reduce perceived danger and to some extent already provide care that includes trauma-informed care.

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Availability of Data and Material The datasets generated and analyzed during the current study are not publicly available.

Code Availability N/a.

Declarations

Ethics Approval The study was approved by Republic of Slovenia National Medical Ethics Committee.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Consent for Publication All authors read and approved the final manuscript.

Conflict of Interest We have no conflicts of interest to disclose.

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