# ‘’WHEN WE CAME HOME, I EXPERIENCED CRISIS” - CAREGIVING EXPERIENCES OF PARENTS WHOSE CHILDREN HAVE UNDERGONE CANCER TREATMENT

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***Abstract:*** *The aim of this study was to gain an understanding of the caregiving experiences of parents whose children have completed cancer treatment. Data was collected across six focus groups involving 24 parents whose children had completed treatment for various types of cancer. Through interpretative phenomenological analysis, the following themes emerged: a) feelings of uncertainty and fear, b) staying in the role of the ill child’s parent, c) the need to learn new parenting skills, d) effect on other children in the family, and e) changes in the parents themselves. Participating parents mentioned feelings of constant anxiety, as well as a range of other kinds of fears they faced upon returning home (fear of medical care not being available on the spot, fear of the unknown, and fear of disease recurrence). They recognised their own altered behaviour toward the child who had undergone treatment (they were likely to limit the daily functioning of their child and act as if the child was still sick). The participants were also aware of the need to learn different, more appropriate parenting skills, as well of the sense of guilt they felt for neglecting their other children. They pointed out the changes in their own physical and mental health, as well as the difficulties they faced in social and work environments. These parents reported that they did not feel sufficiently prepared to care for their child upon completion of hospital treatment. In fact, for some, parent-led care was more difficult than the treatment itself. Our results suggest the need to implement family-oriented follow-up as an integral component of childhood cancer treatment in the Balkan countries. This will help parents alleviate anxiety, balance supervision, and help them adapt to their new normal after their child survived cancer treatment.*

***Keywords:*** *cancer, children, parenting, fears, anxiety, survival*

## INTRODUCTION

Childhood cancer can be one of the most stressful family experiences. The treatment can take a long period of time and it can also have long-term psychological consequences for the parents. Feelings of uncertainty, anxiety, loneliness, depression, and posttraumatic stress symptoms (PTSS) are most prevalent after diagnosis, but these feelings can persist in some parents for years after treatment completion (Eiser, 2004; Lindahl Norberg, 2004; Vrijmoet-Wiersma et al., 2008; Hutchinson, Willard, Hardy and Bonner, 2009; Wakefield, McLoone, Butow, Lenthen and Cohn, 2011). Compared to parents of healthy children, anxiety symptoms involving fear, anxiety, and worry are present in parents whose children have cancer even five years after diagnosis (Vrijmoet-Wiersma et al., 2008). Some parents, especially mothers, report PTSS through very vivid and disturbing memories of their own psychological reactions and treatment-related events, as well as a constant awareness of possible child loss (Kazak et al., 2004). Therefore, emotional distress is not limited only to the acute stress that follows the diagnosis (Lindahl Norberg, 2004). Parental uncertainty regarding absolute cure and possible recurrence permeates the entire disease trajectory (Lin, 2007). Figuratively speaking, the parents have the Sword of Damocles hanging over their head, which symbolises an ever-present threat through fears and feelings of uncertainty, despite successfully completing medical treatment (Zebrack and Zeltzer, 2001; Cupit-Link, Syrjala and Hashimi, 2018).

A parent's question regarding when life "would return to normal" after a child is diagnosed with cancer cannot be answered unequivocally. Upon returning home, parents return to a different reality deprived of the security provided by a hospital stay, with their own emotional scars, uncontrolled fears, and worries, but also with a new perspective on life (Carlsson, Kukkola, Ljungman, Hovén and von Essen, 2019). They also need to learn to live with a changed identity and take care of their own needs that have been neglected during their child's treatment (Dixon-Woods, Young and Heney, 2005; Carlsson et al., 2019). Some parents continue to remain primarily anchored in the role of a parent of a child surviving cancer even after completion of treatment and they are prone to exhibit protective behaviour over the child (Dixon-Woods et al., 2005). An example of such behaviour, given by the authors Ressler et al. (2003) in Dixon-Woods et al. (2005), is parents being prone to accompanying their child to periodical check-ups even when their child reaches adulthood. In contrast to the focus on the child surviving the disease, parents also face altered relationships with other family members. This is especially true for relationships with other children who, during the period of their sibling's active treatment, felt emotionally isolated from their parents, depersonalised, and "being of low priority" in the family system (Van Schoors, Caes, Verhofstadt, Goubert and Alderfer, 2015). In the Balkan countries, however, there is limited empirical knowledge about the caregiving experiences of parents after their child had completed cancer treatment. Therefore, to implement appropriate and timely support programmes, it is necessary to understand the specific challenges and concerns that parents face at the end of the treatment period.

### Research aims

The aim of this study was to gain an understanding of the caregiving experiences of parents whose child has undergone and completed cancer treatment.

## METHODS

### Respondents

This study was carried out with the parents of children who have undergone treatments for a variety of cancer types (acute lymphoblastic leukaemia, osteosarcoma, lymph glands tumour, eye tumour, kidney tumour, and brain tumour). There were 24 parents in total (twenty mothers and four fathers). The age of the children at the time of diagnosis ranged from two to fourteen years. At the time of this research study, the children were between three and eighteen years old. For all children, the total length of treatment lasted between one and two years. Although most of the children completed the treatment approximately three years before the beginning of the study, a small group of children continued to receive maintenance therapy. The maintenance therapy helps keep cancer from recurring following the initial therapy (National Cancer Institute, 2022). Of the 24 parents, 19 did not receive psychological support during the treatment mainly for two reasons, either they felt they did not need it, or it was not available. Those parents who received psychological support attended only one to several counselling sessions.

### Data collection

Data was collected through focus groups. The parents described the course of treatment, their relationship with their children, family members and friends, difficulties they had faced, and changes that the experience of the illness brought. There were six focus groups with session durations between 80 minutes and three hours. The main inclusion criteria for the parents was the fact that their child had completed treatment for different types of cancer regardless of the child's or parent's age. Respondents were not stratified according to cancer type or time after completion of the treatment. The focus groups were conducted during two summer rehabilitation camps for children who had undergone treatment for cancer in the Republic of Serbia. The focus groups were adapted to the parents' daily routines. Each participant was a member of only one focus group. The focus group moderator was one of the authors of the paper, a social worker with sufficient experience of taking part in similar rehabilitation camps. Participation in the focus group was emotionally overwhelming for some parents, which often led to crying, silence, disrupted speech, avoiding eye contact, or asking another parent to continue talking. Considering the vulnerability of these parents, the script for the focus groups changed and they mostly focused on the ‘’telling their story” approach, which included speaking about their personal experiences. In these moments, other parents supported them with encouragement and understanding.

### Research procedure

This research study was carried out in cooperation with the National Association of Parents of Children with Cancer (NURDOR) and “ZVONCICA” - the Childhood Cancer Parent Organisation. These organisations approved the research and provided support during the process of informing and recruiting the parents. The support we received from the associations along with the parents’ awareness of the importance of the research contributed to a good response rate in relation to the total number of parents (n = 57) who attended the rehabilitation camps. All focus groups were carried out before the COVID-19 pandemic. The process of data analysis and writing the article were completed during the pandemic.

### Ethical aspects of the research

The participants were informed about the purpose of the study and the research objectives in oral and written forms by the organisers of the rehabilitation camp, as well as in person by the focus group moderator. We emphasised on the voluntary nature of their participation, the possibility of quitting at any time during a focus group session, and the right to decline answering questions that were deemed too personal or upsetting. When asked, the respondents also gave their consent to record the discussions. Keeping the emotional vulnerability of the participants in mind, they were provided with psychological support by a clinical psychologist if needed.

### Data analysis

Data analysis was conducted upon completing the procedure of interpretative phenomenological analysis (Smith and Osborn, 2008). The aim of interpretative phenomenological analysis is to explore in detail how respondents make sense of their personal and social worlds, as well as how they view particular experiences and events (Smith and Osborn, 2008). To improve our understanding of the experiences that parents go through after their child has completed cancer treatment, interpretative phenomenological analysis was chosen. This analysis includes the following steps: 1) in-depth reading of each transcript several times, and noting all the examples of meaning, comments, and observations; 2) identifying key sentences linked to the phenomenon of interest and grouping them into preliminary themes; 3) grouping and prioritising themes into clusters based on the focus of the research question; and 4) sorting out themes and subthemes, which are shown in **Table 1**. The collected data were analysed by two researchers. The researchers agreed on the key themes and subthemes. Any disagreements were solved by consensus. Computer programs were not used in the data analysis process.

## RESULTS

**Table 1.** *Themes and subthemes associated with caregiving experiences of parents whose children have completed cancer treatment.*

| THEMES | SUBTHEMES |
|---|---|
| Feelings of uncertainty and fear | • Fear of being away from the medical care<br>• Fear of cancer recurrence<br>• Check-ups as a constant source of concern |
| Staying in the role of the ill child’s parent | • Constant worrying<br>• Hindering child in day-to-day functioning<br>• Need for learning new parenting skills |
| Effect on other children in the family | • Feeling of guilt<br>• Missing out on important events in child’s life |
| Changes observed in the parents | • Physical and mental health issues<br>• Difficulties in functioning in social life<br>• Difficulties in workplace environments |

## Feelings of uncertainty and fear

After the period of hospital-based medical treatment where the main focus is the child's struggle to survive, parents face new challenges associated with returning and adapting to life after completing cancer treatment. One mother describes this period of "getting back to normal" in terms of deep and more paralyzing fears - *"I completely agree that the fears are bigger afterwards and that this stress… Then you feel the adrenaline flowing for the first period of time, maybe even for a few months. You're fighting, you have only one dream, and that's his life, you don't think about anything else. And we don't care about anything else. Then, when you really start getting back to normal, those paralyzing fears come up." (M3_FG3).* Upon completing the cancer treatment, the parents stated that they dealt with a variety of fears: the fear of being away from medical care, the fear of cancer recurrence, and the fear of the unknown between medical check-ups.

### *Fear of being away from the medical care*

The parents perceived the hospital stay to be "easier" because of the availability of medical staff, while upon returning home, they shared their fear of being away from medical care and fear of the unknown. One mother shared that when *"we finished with the maintenance, when we came home, I experienced crisis. It was then when he literally became my concern. I was supposed to take care of him, I mean, in two weeks he's having a check-up, but what should we do in the meantime… What if this happened? What if that happened?!" (M4_FG3).*

Another mother shared that *"…it is somehow harder now when I returned home than it was in the hospital because it was easier in the hospital, the doctor was there and somehow I felt safer, later when I returned home, those two months were terrible and the only thing I had in mind at night was to put them to sleep and to go to sleep myself" (M2_FG6).*

Besides the sense of safety that doctors gave to parents during the treatment, the medication in the maintenance therapy contributed to their sense of safety. The parents were worried about the discontinuation of the medication and were fearful of the unknown, which typically follows such a decision. This is illustrated by a dialogue between parents:

*"…we are about to end the medical treatment and I'm asking myself what to do without the medications. They are, let's say, a kind of… I don't know how to say… They are some kind of safety, what he was taking, and now when it suddenly stops I still wonder what next, how to behave, how to deal with it, what to do next" (M1_FG5).*

*"We are still, you know, in the process of maintenance therapy. I don't know what it will be like next year, when we will no longer have been in the process. I hope that the day when he stops taking the medication will not be terrible." (M2_FG5).*

### *Fear of cancer recurrence*

Parents revealed a conspicuous fear of cancer recurrence, which is described by one mother as "a worse experience than the disease", she added, *"I guess that during the treatment I didn't have time to fear, being with him day in day out… but now, you know, I feel this fear. I'm afraid of the recurrence. That's what's worse than the disease" (M3_FG3).* The fear of recurrence does not allow parents to relax, since the upcoming medical check-ups continue to foster that fear: *"Well, I always have some kind of fear. I simply can't be one hundred percent relaxed because there is always the fear that it might come back. Every three months we have a check-up and when it's getting closer, I feel nervous and scared. I'm not one hundred percent relaxed, and I can't be" (M1_FG2).*

### *Check-ups as a constant source of concern*

The parents perceived the periodic check-ups as a constant source of concern, fear, and anxiety. They said that a common cold and an increase in leukocytes *"triggers the alarm (M3_FG5)"*, makes their *"blood run cold (M4_FG4)"* and they felt *"scared to death (M4_FG3)"*. One mother said that even a slight increase in leukocytes would lead her to a nervous breakdown. For example, she shared that *"[s]he [the child] had a* *temperature two days ago. When the doctor said the leukocyte level was 5.5, I think she hasn't had that level ever since she started the treatment. Only when she was on Dexazone, the leukocytes were higher. I think it made my blood run cold, till the doctor said it was nothing bad. So, every time she has an infection or the leukocytes are high, I'm having a nervous breakdown" (M4_FG4).* One father explained that *"[t]he check-ups aren't problem for me. The problem is when I take a look at the blood count, what I will see. Everything is OK before and afterwards. I really got scared at the last check-up when the blood count was bad. That was a disaster for me" (T2_FG2).*

## Staying in the role of the ill child's parent

In addition to the aforementioned fears, the parents showed particular behaviours that prolong the existence of the disease in the family. The parents cited constant worrying, a tendency to hinder the children in their day-to-day functioning, and the awareness that they needed new parenting skills suitable to look after childhood cancer survivors.

### *Constant worrying*

Although the time has passed since cancer treatment, some parents reported that fear, anxiety, and the worry about their child's health condition were still very present. “Thinking too much ahead”, as stated by one mother, turns into “a complete panic“. She elaborated that *"[w]hen everything is just as it should be, then you start thinking, if there'll be some consequences and so on ... Actually, I start thinking too much ahead and, from time to time, I still have those fears ‘And what if?’ ‘And what if. Yeah, and it overcomes me, and then I have a panic attack—fall into a complete panic, I lose my head, and I tell to myself ‘Well okay, if everything goes bad, what can I do? Is there anything I can do? No there isn't." (M3_FG5).*

Another mother points out that she tries to hide her fears in front of her daughter and lets her “live like any other child”. She is aware of her personal changes and her constant worrying: *"Years have passed, the worry never stops, and that's for sure. You'll never be what you were before this, but you should never ever show her that you're worrying. I'm struggling with it all the time and I'm actually trying to control myself and let her live, live like any other normal person" (M2_FG5).*

Some parents reported that returning to their “old” life was no longer possible because of the constant worrying and fears. “*Fears are still present. I started working in March, but before March it was like... it was claustrophobic. A bruise. Why do you have a bruise? A million questions and follow-up questions. I think that I returned to a normal life, so to speak, though it will never be a normal life to me. There is always a feeling of panic, and a kind of fear... What to do next?" (M1_FG5).*

### *Hindering child in day-to-day functioning*

After completing cancer treatment, the omnipresent fear for the child's health was confirmed by the parents' behaviour, which hindered the children in their day-to-day functioning. Even though the intention of the parents was to protect the child, the children were prone to social isolation, excessive control, and restrictions imposed on them. The parents described it as follows: “... *when we returned home, no one could come by, we weren't supposed to go anywhere and he suffered a lot, he really suffered... Later, as spring was coming, we cut him some slack and we started going to the park. We're still under maintenance therapy. I don't know what it will look like next year when we're off the therapy. I hope it won't be bad." (M1_FG6).*

*"I started making mistakes, like, he takes one step forward, and I take him three steps back. He takes two steps forward, and I take six steps back. I don't let anyone visit us, and we don't go anywhere. God forbid if someone sneezes out in the street, it's like run like hell away from them. He always wore a protective facemask until the director of a kart-racing centre where we went for a race simply took it off and told me that I needed to talk to someone. Eventually, I went to hospital to see a*

*psychologist. I somehow managed to overcome it, without him noticing it." (M4_FG3).*

"I always have to keep an eye on her" is an excessive need for control over and dread for the child. One mother describes it as "*... at first it was so much easier both for me and her when she got the catheter, but now it's a huge problem. What to do when she's playing with other kids? I'm afraid someone could... They don't even have to knock her over... If a kid trips and accidentally grabs her while falling down... I think about these things all the time, I mean, I have to dread. And I have to always keep an eye on her... Even when she is on the playground slide, and all the time." (M4_ FG1).* One mother says that she was prone to saying "no" to whatever her child wished for: *"I might have made the mistake of not letting him do what he wanted, for example now and then, as any other teenage boy, he wants to stand out with his peers, I don't know, then I remind him of everything: 'You know that you can't, don't do it'. And he says 'You never let me do anything!'" (M3_FG6).*

### *Need for learning new parenting skills*

The necessity to "learn how to behave toward the healthy child", as described by the parents, arises from maintaining the role of the parent of the ill child, even after the ill child had completed the cancer treatment. The parents said that they kept treating their children as if they were still ill. At the same time, they were aware that neither the children nor they benefitted from this kind of relationship and that they needed different skills. The need for learning new parenting skills was recognized by doctors, spouses, and parents, which is illustrated by one parent *"...to simply do the same as the parents of healthy children... when she comes from school 'Hey, Dad, I have a bruise', and I say 'OK', and that's it." (T1_FG5).*

*"The doctor comes to me and says 'Listen, woman, back then we tried to teach you how to behave towards a sick child, and now it seems you have to learn how to behave towards a healthy child." (M3_FG5).*

## Effect on other children in the family

Reflecting on the relationship with their other children in the period after treatment was completed, some parents say that they felt guilty due to unintentional emotional neglect they caused and because they were missing out on important events in their other child's life.

### *Feeling of guilt*

One mother talked about that feeling in the following way: *"Yeah, but we neglect that healthy child... it's not on purpose... I know it, we neglect healthy children... It's been for a long time. And since then, she's become introverted and she's shut us out. She rarely wants to speak with me or anyone else. I noticed that I made a big mistake...I can't make up for this." (M2_FG2).*

*„The other mother stated: "I wasn't there for my daughter for almost two years... That's terrible.... I can't turn back the time and fix it.... I feel so guilty because of it and I have to live with it." (M1_FG1).*

### *Missing out on important events in a child's life*

The parents pointed out that their unintentional absence was the reason for missing out on important events in their other child's life and that they could not make up for the lost time. Some parents had difficulties in expressing feelings in their relationship with their healthy children and they noticed that these children were closed off to them. *"I'm crying, I left my girl at home, it's her birthday, and I'm in the hospital... She's about to enrol into the first year, and she's alone. She calls me: 'Mom, we have a prom'. I wasn't there to buy her a dress, to get her ready for her night. It hurts me a lot... Even today she comes to me, sits in my lap, I mean, she's pestering me, and she sits on me, I almost burst into tears. She says: 'Mom, kiss me too'. My heart is about to break. 'What's wrong, Mom? Kiss me too'. I tell her that she's my girl and she says: 'I know I'm your girl, but I also need your love'. Then I want kill myself, you stupid woman, I'm as cold as steel. I don't know how to explain it. I somehow can't express my feelings and emotions." (M3_FG6).*

### Change in parents

Besides the constant concern for their child’s health and the need for developing new parental behavior patterns, some parents of children who have completed cancer treatment become aware of the changes in their physical and mental health, as well as the difficulties they face in functioning in their social life and workplace.

#### *Physical and mental health issues*

The parents report some changes in their physical health: *“I got sick, I have high blood sugar and other stuff, my hormones have gone crazy.” (M2_ FG3),* as well as in their mental health: “*I went insane. I completely lost my head.” (M3_FG6).* One mother says that her physical and mental health have changed: *“And then after three years, I started having problems. I kept it somewhere deep inside me, in the sense that I wanted to spare everyone around me, my mother and father, my husband, I mean, it hurts so much, it hits you when you’re the weakest. It started suffocating me, my high blood pressure, the cysts, smoking, and so on, panic attacks, but yes, I started, I mean, I’ve started taking antidepressants.” (M3_FG3).*

#### *Difficulties in functioning in social and workplace environments*

They also noticed difficulties in functioning in social and work environments. One father described it as follows: *“For a certain time, for a couple of months, I cracked up. I wanted to quit my job, everything bothered me, but it lasted for a short time. Everything was getting on my nerves, even my colleagues, the clients, the boss, everyone. It was a short period of time, but, as I said, it passed by fast.” (T2_FG2).*

After completing cancer treatment and returning home from the hospital, the parents reported having difficulties in adapting to social life like they used to before the illness. They noticed that they were best understood by parents of other children who were ill. Some parents pointed out that they did not spend time with or talk to some of their friends anymore, and that they would engage in topics that didn’t include details of the cancer treatment when talking to those friends that they chose to spend time with. *“The biggest problem I had was to adapt to the old life, to fit into my company. At the beginning, I wasn’t able talk to anyone. It’s because… The thing I went through, what I saw… No one in this world could understand it, except the parents who went through the same thing.” (M4_ FG1).*

## DISCUSSION

The results of this research study contribute to a better understanding of the specific challenges that parents face after their child completes the active part of cancer treatment. Upon returning home, the parents in our study experienced a number of crises in their parental role. Consistent with previous research (Peikert, Inhestern and Bergelt, 2018; Carlsson et al., 2019), the transition process of the “return to normal life” was reported as stressful, often presenting a significant challenge for the entire family. Similar to the findings of a study by Wilford, Hopfer and Wenzel (2019), parents in the present study did not feel sufficiently prepared to care for their child upon the end of hospital treatment, and for some parents, it was more difficult than the treatment itself. Our research results suggest that the parents then reacted in different ways, including expressions of fear, feelings of uncertainty, and constant anxiety. Wilford, Hopfer and Wenzel (2019) explained that the uncertainty and anxiety typically comes not so much from objectively challenging circumstances, but from the parent’s response to the loss of safety and a safe, well-established routine, symbolized by the hospital, during difficult medical treatment. According to Björk, Nordström, Wiebe and Hallström (2011), parents find themselves in “unchartered territory”. Apart from the safe harbour represented by the hospital and the medical care provided, the prescribed drug therapy represented significant safety support for the parents in the present study. They feared a future that excluded taking medication and did not know how to cope with it. This is consistent with findings from previous studies (Björk et al., 2011; Carlsson et al., 2019). Therefore, parents need support when learning how to cope with feelings of uncertainty and constant anxiety. They need to be better prepared for the period after leaving the hospital and the discontinuation of maintenance therapy.

As reported in other studies (Wakefield et al., 2011; Cupit-Linka et al., 2018), the parents in our study also feared disease recurrence. The experience of the illness was found to have eliminated their sense of invulnerability about their own lives and that of their family, and some were facing ongoing fears that the illness might return (Van Dongen-Melman, Van Zuuren and Verhulst, 1998). They had undergone an experience where even the most unlikely – and most unwanted – events can occur (Lindahl Norberg and Steneby, 2009). One mother described potential disease recurrence as "a worse experience than the disease itself", while Björk et al. (2011) reported that disease recurrence is "the worst word in the vocabulary you don't want to hear". The parents in the present study associated the fear of recurrence of the disease in common colds and infections, increased number of white blood cells, bruises on the body, and so on. Walker, Lewis, and Rosenberg (2020) point out that parents can see the fear of recurrence in symptoms such as fever, fatigue, or lower appetite. Furthermore, Björk et al. (2011) stated that the fear of recurrence is easily triggered when, for example, parents see their child feeling unwell, or when a sick child they become acquainted with in the children's ward suffers a relapse or dies. Periodical check-ups are often a trigger for re-experiencing traumatic moments of the acute treatment period. On the one hand, parents need support while preparing for check-ups in a way that increases their sense of control, for example, by focusing and asking questions related to their child's actual health status. On the other hand, they also need help in decreasing the level of anxiety about possible disease recurrence by accepting that they do not have control over it.

Several parents who participated in our study noticed that they showed symptoms of PTSS – they would go into social isolation, their interests and view of the world became narrow, and they were unable to come out of constantly worrying about the possible danger for their child. Several studies have suggested that parents of survivors may have elevated rates of PTSS compared with controls and the general population and they may be more likely to experience PTSS than their surviving children (Barakat et al., 1997; Kazak et al., 1997; Taïeb, Moro, Baubet, Revah-Levy and Flament, 2003).

Constant worry and fear often lead to excessive control and restrictions for the child, as a part of the idea to "stop everything" and keep the child healthy. The parents in our study expressed that they exhibited several protective and regressive behaviours towards their children. They were prone to social isolation, as well as excessive control when it came to setting restrictive rules that the children had to follow. This is again consistent with previous studies (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp and Mullins, 2010; Ljungman et al., 2014). Norberg and Steneby (2009) explained that the experience of a potentially fatal disease can serve as a background for such overprotective behaviour. Similar to the findings of Williams, McCarthy, Eyles, and Drew (2013), the parents are aware of the fact that their managing aspects of the disease are deemed too upsetting, detailed, sensitive, or age-inappropriate for the child.

While parents in the present study were focused on caring for the child who was the cancer survivor, they pointed out that they neglected their other healthy children and felt guilty about it. In a study by Lindahl Norberg and Steneby (2009), from time to time, healthy siblings ended up in the periphery of the family. Peikert et al. (2020) claimed that 16 out of 26 families with more than one child reported that siblings received less attention from their parents, which made many parents feel guilty (Carlsson and el., 2019). A parent's feeling of guilt and sympathy for the ill child are reported to be linked to perceptions that the ill child is more vulnerable and in need of additional attention and support than healthy siblings (Williams et al., 2013). Due to this emotional neglect by the parents, healthy children may feel rejected (Ortiz and de Lima, 2007). It is important to help the parents tolerate the feelings of guilt, while simultaneously supporting them to find time to take care of their healthy children. Thus, spending time together does not trigger a constant memory of the period when they were apart.

Our study also indicates that parents recognise changes in their own physical and mental health. They stated that the constant worrying and exhaustion often lead to difficulties such as high blood pressure, panic attacks, irritability, and so on. Previous studies (Norberg and Steneby, 2009; Carlsson et al., 2019; Wilford et al., 2019) found that psychological exhaustion also includes symptoms such as fatigue, susceptibility to stress, cognitive symptoms, sleep disturbances, tiredness, nausea and headache, uncontrollable physiological arousal symptoms, unexplainable anger, irritability, and loss of patience for other family members, panic attacks and anxiety, excessive weight gain, and endocrine dysfunction. The results of our study also point out that, at the end of the active hospital treatment, parents experienced difficulties in functioning in the work environment and in their network of friends. They had gone through a traumatic experience that was incomprehensible to the majority of other people. Van Dongen–Melman, Van Zuuren and Verhulst (1998) stated that due to such a traumatic experience, parents feel a sense of loss of their former lives and their child’s former self.

The parents in the present study realised that they needed new parenting skills because their existing knowledge and skills left their children in the role of “the child who was still sick”. They needed to learn how to parent a childhood cancer survivor, as well as how to handle their day-to-day parenting responsibilities, but there are not enough resources for gaining this knowledge. Parents also need help in understanding that if they are not taking care of themselves, they cannot be helpful to their children. To find an easier way of coping with the “unchartered territory” that they feel they find themselves in at the end of treatment, the implementation of a structured follow-up was proposed by Björk et al. (2011). Professional psycho-social support could help families with the process of reintegration (Peikert et al., 2020).

For example, in Germany, a family-oriented rehabilitation (FOR) programme is implemented, which addresses patients with childhood cancer (> 15 years), their parents, and healthy siblings. The programme provides individual or group therapies and activities as required for all family members with the help of multi-professional therapeutic teams that include physicians, clinical psychologists, social workers, and other professionals. Structured rehabilitation programmes can help these families to prepare for reintegration based on a multidisciplinary approach (Inhestern et al., 2020). A review of evaluation studies shows that parents, childhood cancer patients, and healthy siblings benefit from the FOR programme, since it helps to stabilise the family unit and improved the mental health of the parents (Inhestern et al., 2017; Krauth, 2017).

The results of this research study suggest that the content of such a multidisciplinary follow-up in the Balkan context should include care guidelines that balance supervision and freedom, alleviate parental anxiety and help them find new parenting skills that will suit them better after they undergo a traumatic experience, while accepting the human existential limitations in controlling everything life can bring, and finding meaning in life as it is unfolding in front of them.

## Research limitations

The results of this study are not generalisable since a purposive sampling strategy was used. All the parents who participated in this study were associated with variation in terms of their child’s cancer, the age of their child, and the length of period after treatment completion. In future research, parents could be grouped according to these categories for further analyses. For example, difficulties that the parents faced upon returning home could differ considerably depending on whether the child in question was a pre-schooler or a teenager. Selection based on a predetermined criterion of the children’s age would contribute to a deeper understanding of the matter. Furthermore, the predominance of mothers over fathers was another limitation of this study. The fathers’ perspective was present to a lesser degree than mothers’, and further empirical studies should work on correcting this imbalance. Considering the emotional vulnerability of the parents and the fact that the focus group leader in this study did not have any clinical experience with traumatised populations, it is suggested that future research projects should engage a leader or a co-leader with clinical expertise.

### Implications for practice

The results of this research represent a step forward in the research of the caregiving experiences of parents in the Republic of Serbia whose child has completed cancer treatment. Our findings can help medical staff, professionals in assisting fields, other public domains interested in this topic, and parents of children suffering from cancer. The results can also be used as guidelines in creating a programme of support for the family after the child has completed the cancer treatment. The knowledge gained can also help other Balkan countries with similar healthcare systems, where family-oriented follow-up programmes are not developed and do not constitute an important part of the process of treatment. Our research indicates that strong support is necessary for the parents in re-establishing the old, empowering the neglected, and/or developing the new roles after going through the experience of their child's illness. In addition, parents need support related to well-balanced childcare, taking care of their own mental health, and in relation to the influence the child's cancer on overall family and social functioning. Well-balanced care, in this context, would mean supporting parents to find and empower the spontaneous and flexible aspect of their role as a parent, alongside the caring and controlling one. Available sources of medical and psycho-social support could be of great value in moments of overwhelming anxiety and worrying. This would also help eliminate and reduce psychosomatic symptomatology. By establishing a family-oriented follow-up programme, parents and their other children can be helped in the process of integrating losses related to the time lost and reduced emotional care, and at the same time, encourage them to create different ways of rebuilding and strengthening family ties. A child suffering from cancer is an experience that is rare and unexpected for most parents. Multi-professional therapeutic teams (through group or individual work) can help parents who experienced their child having cancer and undergoing cancer treatment to consider a new perspective on values, question existing relationships, and set these relationships in different new constellations.

## CONCLUSION

The results of this research study contribute to improving our understanding of the parental caregiving experience after their child's medical treatment has ended. Parents describe facing several stressors after leaving the hospital, reflected, for the most part, in the way they take care of their child after the medical treatment ended. They also reported their altered relationships with other children, altered physical and mental health, as well as difficulties in fitting back into their social and work environment. They emphasised the fact that they did not feel prepared for taking care of the child after the end of treatment, some parents even mentioned leaving the hospital and coming back home as something more challenging than the treatment itself. During the period of medical treatment in the hospital, the parents in our research study were unintentionally emotionally neglectful towards other children in their family. The parents remember some decisions and sets of behaviours induced by feelings of fear and/or worry. They also shared that they were aware of the need to reassess their parenting skills in accordance with the child's needs, while taking their other children's and their own needs into consideration. It is of vital importance to have a family-oriented follow-up programme as an integral component of treatment in the Balkan countries. Such a programme should, among other things, aim to help parents find their footing in relation to events within and beyond their control, and help them enrich their own existential and humanistic realisations made after undergoing this specific and demanding experience.

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