# Needs and Difficulties of Parents with Children Suffering from Malignant Diseases

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## **Abstract**

Malignant diseases are one of the leading causes of death in children in developed countries, although constant progress in therapy is continuously decreasing mortality. The diagnosis of malignant disease is a significant stressor in the life of a child and its family, significantly affecting the quality of life for the entire family. It constitutes the prototype of a stressful situation and a disease with a potentially devastating effect on the child and its family. This paper discusses 50 professional and scientific papers published between 1993 and 2022 that explore the needs and difficulties of parents of children with malignant diseases. To provide adequate help and care, a correct evaluation of the problem and parents' needs is required. For the parents, the diagnosis of a malignant disease for their child constitutes a psychological and existential challenge. To meet the parents' needs, as well as to ease their problems, further research - in most cases also supported by the parents themselves - is needed to help them cope with this extremely stressful and hard part of their lives.

## Introduction

According to the Croatian Institute of Public Health, in 2019 in the Republic of Croatia, a total of 149 children and young people under the age of 19 fell ill with some form of malignant disease (1). Malignant diseases are one of the leading causes of death in children in highly developed countries, although improved therapy for children with cancer has led to a significant increase in survival rates (2). The resulting stress of the parents of a child with malignant disease is extremely high and significantly affects the quality of life of the whole family (3,4). Previous research has shown a variety of parental reactions, and higher levels of anxiety than in the patients themselves (5). In addition, long-term treatment of a child with a malignant disease causes a state of chronic stress in the parents during this period (6,7). Apprehension, anxiety, depression, and other psychological symptoms are most intense during the active phase of a child's treatment, but over several years they slowly decline and become comparable to levels in the community sample (8).

On the other hand, parental reactions to a child's illness such as symptoms associated with traumatic stress, feelings of helplessness, insecurity, and low self-control were noted many years after the child's treatment was completed (9-12). Some studies show that a child's malignant disease leads to intensive participation within the health system, which requires adjustment and provision of information and can lead to emotional exhaustion of parents, disturbed relationships between family members, stigmatization and alienation, as well as significant changes in the daily life of the family (3,13,14). Most research to date shows that parents express feelings of guilt, anger (15), feelings of insecurity, loneliness, loss of control (16), financial difficulties (17), mental exhaustion manifested as fatigue and increased sensitivity to stress, symptoms of post-traumatic stress disorder (5,10), and sleep problems (16). However, the ability of parents to manage their psychological changes during a child's cancer treatment process is vital, not only for their solace, but also for the impact on the child's well-being (18) and long-term social adjustment (19,20). The parents of a child with malignant disease react in different ways. Most of them go through five basic stages: denial, anger, negotiation, depression, and acceptance according to the Kubler-Ross model (21). Being familiar with these reactions, taking into account the time at which each reaction occurs and their duration, we can find out what really saddens parents, what problems they face and what their needs are during and after the treatment process of their child. In addition to the difficulties mentioned so far, a recent study by Anna Lewandowska from 2022 speaks of the very pronounced need of parents for psychological help, emotional support and the provision of information. In her research conducted over five years, she found that the health care system does not currently meet the needs of parents of sick children, so it is necessary to explore mechanisms by which health care providers can identify and meet the needs of parents (22).

The aim of this paper is to determine the needs and difficulties faced by parents of children with malignant diseases during and after hospital treatment, based on available research. In addition to identifying the needs and difficulties of parents, the paper will discuss an ethical dilemma about the involvement of parents of children with malignant diseases in research.

#### Methods

A review of the literature related to the needs and difficulties faced by parents of children with malignant diseases was made. Emphasis was placed on the period during the child's hospitalization and the period after treatment. Medline, PubMed and CINAHL databases were searched using the key words: pediatric cancer, parent satisfaction, parent needs, issues, hospitalization, and ethics. 50 professional and scientific papers were reviewed. Only papers with the entire available text were taken into account. The search was limited to the period between 1993 and 2022.

## The ways parents cope with their child's diagnosis of malignant disease

In order to better identify the needs and difficulties of parents of children with malignant diseases, we

need to know what are the normal, expected reactions of parents, and what are acceptable coping styles after learning about a child's malignant disease. Most parents are not ready for their child to be diagnosed with a malignant disease (23). The lifethreatening nature of the disease and its intensive treatment cause many psychological, practical and emotional difficulties for parents. Coping with fear becomes an inseparable part of life. Fear of death, fear of the unknown, and thinking about one's own capabilities and limitations arise. Being faced with a diagnosis of a child's malignant disease causes a variety of emotional reactions. Reactions change simultaneously with different stages of the sick child's treatment (24).

In the first days and weeks after diagnosis, parents describe the reactions they experienced as if they were caught in an emotional whirlpool or a nightmare. Most parents who go through this period share similar feelings, but the ways parents are willing to voice or express those feelings vary. The way they deal with their emotions is marked by their own life experiences, cultural differences and their personal coping styles. According to distinguished authors in the world of research on human emotions and reactions such as Dr. Kubler Ross, five basic phases that a person goes through during a certain traumatic situation (and that we consider acceptable) were identified. The phases, popularly known as DABDA, include the following:

- 1. Denial
- 2. Anger
- 3. Bargain
- 4. Depression
- 5. Acceptance

Some researchers are trying to disprove Dr. Kubler Ross' model, such as George Bonanno in his book "The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After a Loss" in which he states that most people do not grieve and that the lack of grief and other phases is a good outcome after a traumatic event. Literature research done for the purposes of writing this paper does not confirm George Bonanno's assertion. Some parents experience certain emotions for a longer time, some remain in a certain phase for years, while others skip phases. That parents are indeed in a state of chronic stress is confirmed by research on neuroendocrinological measurements in parents of children with ma-

lignant diseases (7,25).

After hearing the child's diagnosis, parents are often shocked and confused, they stop listening, do not remember what was said and are not able to think clearly. Healthcare professionals and others involved in the information process need to be aware of possible reactions from parents, to help them in their state of shock. Some parents cannot cope with bad news and can react very aggressively and even physically attack medical staff (26). It has been found that the way healthcare staff respond to parents' feelings and their behavior can affect the parents' ability to absorb the initial shock and begin to adapt to the child's illness. The range of emotions that occur in parents is wide (and includes feelings such as fear, guilt, anger, dullness, hopelessness, and sadness), whereas coping styles in parents differ. After the initial shock, parents can quickly turn to positive thoughts, preoccupy themselves with certain details of illness or treatment, seek support from relatives and friends, find hope in religious beliefs, etc. (26).

Research to date has shown that the way bad news is presented to parents is the most important part of the process of treating their child. For this reason, several recommendations and protocols have been drawn up for medical staff on how to communicate with parents of severely ill children (26-28). The summary of this chapter is that all the reactions and coping styles expressed by parents after hearing a child's diagnosis can be acceptable and expected. They are mainly determined by the time period and various phases that can be identified based on their behavior. Proper recognition and acceptance of parental reactions and coping techniques, without condemnation, are imperative for medical staff.

## Needs of parents whose children are suffering from malignant diseases

Previous research conducted with parents of hospitalized children recognized that there is no systematic approach to parental contribution to a child's recovery. There are parents who are maximally involved in the care of their child, as well as those who are less involved, because it is too stressful for them (29). After recognizing the positive impact of roomin, i.e., allowing a parent to be with their child during a hospital stay, a survey was conducted in Iceland in the 1990s on self-assessment of parents' satisfaction with their needs being met. One of the most im-

portant self-assessed needs of parents was the possibility of staying with the child 24 hours a day and this need was fully met in all respondents (30). The shortcoming of this research is the small number of respondents (32), making the result unsatisfactory in a wider sense because there are parents who were not included in the research and who were not able to be with their child. Parents are nowadays considered to be partners in the care of their child during hospitalization. It is necessary to determine clear boundaries of parental partnership and set boundaries for their participation in the process of caring for a sick child. The needs of parents whose children have a malignant disease differ from the needs of parents whose children are not seriously ill and depend on the emotional state of the parents at a given time. Research conducted by a nursing professor Linda Shields highlights 9 basic needs that parents listed as most important and which are not impacted by demographic diversity. The research was conducted in Sweden, England, Indonesia and Australia and was compared with the opinion of medical staff on the needs of parents. These are the statements about the needs that parents and medical staff have singled out as very important:

"We want to be sure that, even though we are not present, our children will receive the best possible care."

"We want to get advice on our child's care before discharge from the hospital."

"We want to be informed about all the procedures that will be performed on our children."

"We would like to be capable to take part in caring for our child."

"We want to be able to stay with our child for 24 hours a day if we want to."

"We want to be sure that, even though we are not present, our children receive the best medical care."

"We would like nurses to recognize and understand parents' feelings."

"We want to feel that we are important in contributing to the well-being of the child."

"We want to get accurate information about our child's condition" (31)."

Parents of children with malignant diseases often have greater needs for emotional support, understanding, and information (31-34). Parents' needs are met when they are satisfied with the overall care for the child, but also themselves during and after treatment. In addition to the needs of the parents, it is important to highlight the needs of children, especially adolescents whose needs may be different from the needs of their parents (35). To ensure parent satisfaction, it is necessary to continuously evaluate care, meet needs and constantly adjust relationships with parents, which is possible only through continuous research and the application of research results, and should not be limited to uniform approaches aimed at meeting the needs of all parents. There are precisely prescribed programs and interventions (according to research results), on how to help parents, and how to guide them through the process of their child's treatment. One of these programs was created in Philadelphia in 2004 and is based on 4 basic principles:

- 1. Establishing trust with parents and understanding and accepting their views.
- 2. Facilitating interaction and communication between parents, medical staff and the sick child.
- 3. Helping parents alleviate feelings of loneliness and understanding other feelings that parents encounter.
- 4. Focusing on the family's strengths reflects the perspective that parents and families are competent, able to adapt to adverse circumstances, and to continue growing and developing as a family despite their child's illness (36).

In addition to parents' needs related to the health system, there is also a need for better understanding between partners. In certain phases of the child's treatment, i.e., often during the initial period of diagnosis, partners and family are close-knit (37). But with the passage of time and increasing demands for treatment, relationships between partners and families become strained: 6 to 41 months after diagnosis families of children suffering from the malignant disease can fall into very different and rigid patterns of behavior compared to members of other families (13). Research conducted with both parents speaks in favor of a greater need for psycho-emotional help to mothers than to fathers, although fathers also state a great need for help (38). Precisely because of the child's life-threatening condition, the immediate focus for medical staff is the child's survival, while special supportive procedures by psychologists, social workers, psychiatrists, nutritionists, occupational therapists and others are delayed until problems arise. This is unfortunate because the timely inclusion of all necessary professions in the care of children and parents would have a positive effect on further coping with malignant disease (39).

Croatian hospitals, especially those treating children with malignant diseases, provide organized care by psychologists, social workers, social pedagogues, physicians, nurses and special-needs educators. How accessible they are to parents and children, and how successful they are in their interventions is difficult to assess due to a lack of feedback from parents. There is very little research or papers in Croatian that would contain feedback from parents on the satisfaction of caring for their child and meeting their needs. In Croatia, children receive the best possible treatment - the only difference being that in Europe and the world there is a better support system for children and parents. These systems are more sensitive to parents' needs, they continuously cooperate with them and ask them about their opinions. They rearrange departments according to the real needs of children, build palliative children's centers and invest a lot in the satisfaction of children and parents. They are more advanced in this segment of help because they know exactly what the needs of parents are, and they know that because they conduct research with the parents' help.

Difficulties faced by parents of children with the malignant disease during and after the child's treatment

Few studies deal with difficulties faced by parents of children with malignant diseases. Research has mainly focused on emotional stress and post-traumatic stress disorder (PTSD) in parents, and generally on parents' satisfaction with hospital care (3). In 2004 in Croatia at the University Hospital Osijek, a study was conducted about parent satisfaction with hospital care. From this study, we can single out the following remarks and difficulties: dissatisfaction with communication between physicians and nurses, lack of physician's time, lack of kindness and sufficient care, dissatisfaction with cleanliness, food and beds, and dissatisfaction with long waits for diagnosis (40). There is no targeted research on the difficulties that parents face in Croatia. At the 2012 session of the Croatian Parliament, the parents of children with malignant diseases presented the difficulties they face in front of the working group of the Coordination of Associations for Children, which monitors the implementation of children's rights in the health system. They pointed out the following:

- The right of the child not to be separated from its parent (a comfortable chair beside the child's bed would suffice).
- The right to respect personal dignity (the child is spoken about as if it were not present).
- The child's right to privacy is not respected (examinations are performed in the presence of persons unknown to the child).
- Information about the child's health condition is denied, or given to the child in an incomprehensible way, or given to the parents in an extremely inappropriate way.
- Children are denied the right to freely express their feelings (sadness, fear, anger, loneliness).
- The child is deprived of a safe place (painful examinations and minor procedures are also performed in its hospital bed).
- Children are not prepared for examinations, or medical procedures.
- There are not enough staff to take care of the children's psycho-emotional well-being and to provide professional support.
- Emotional support is also lacking when a child is forbidden to wear its clothes during hospitalization, to have things around it that are important to it, and when peer visits are forbidden.
- The support for families whose children are seriously, chronically, or life-threateningly ill is insufficient in the health care system.

In 2012 in Belgrade a study was conducted about difficulties faced by parents of children with malignant diseases. The aim of the study was to gain insight into the difficulties that parents faced through different phases of treatment – after learning the diagnosis, during hospital treatment and after the end of hospital treatment. Parents describe being informed about the diagnosis as a strong shock (13). In the initial period, some even had suicidal thoughts. Their biggest concern was how to communicate the diagnosis to the child. During the hospital treatment, their mental and physical health was impaired (changes in eating habits, depression, emotional and physical exhaustion). They describe the child's physi-

cal changes as the most disturbing experience. Some parents blame themselves for the child's disease and that is an additional burden for them. They express concern for a child experiencing behavioral changes (e.g., refusing to communicate). Hospital treatment is followed by a phase accompanied by fear, insecurity and a feeling of incompetence in caring for the child. Parents are wondering if they will be able to take responsibility for their child after completing hospital treatment. They cite fear of relapse, or of follow-up examinations, and not being able to adjust to a "past" lifestyle (13). In an extensive study by Patterson et al. (2004), several difficulties faced by parents were found, which they divided into four important segments:

- 1. Difficulties related to treatment (side effects caused by chemotherapy or radiation, infections, hair loss, impaired concentration, loss of limbs, periodic surgery...).
- 2. Difficulties related to the child (feeling of fear, nervousness, loss of daily routine and activities, concern about the cost of treatment).
- Difficulties related to the family (during diagnosis and treatment feeling of being overwhelmed, helplessness and loss of control, fear that the child will die, guilt due to the child's pain, self-blame due to the child's illness).
- 4. Difficulties related to the community (insensitivity of family friends, lack of support groups, non-cooperation of the school, lack of competence of health professionals which did not apply to oncologists, however) (41).

Large systems can be sluggish, difficult to change, and insensitive to the individual and further create difficulties for parents who are already in a difficult situation. To avoid a child's prolonged stay in the hospital and the possibility of increasing the chances of difficulties, for some or even most of the hospitalized children, day hospitals may be the solution. This would be a more considerate way of treating children and would reduce the psychological trauma for the child and family brought about by classical hospitalization. Family participation in treatment as well as the child's overnight stay at home contribute to a faster recovery (42). The difficulties that parents of a child with a malignant disease face are usually very individual. They depend on the diagnosis, emotional maturity and age of the parents, and other family members. They vary significantly from hospital to hospital. They depend greatly on the medical staff and the parents' perception of the health care system. It is necessary to purposefully investigate the difficulties that parents face and enable them to express themselves without restraint and hesitation about the problems at hand. The research done on this topic was mostly initiated by nurses. The degree of parents' satisfaction with medical care largely depends on them and they recognize this. Involving the parent as a partner in the care for the child and finding a common level of communication results in a higher degree of parental satisfaction and fewer difficulties (43).

## Parental strengths - coping and adaptation

In everyday life, coping, adaptation, and adjustment mean the same thing: how well a person copes with certain aspects of his/her environment. Adaptation in a broader sense means accommodation to environmental requirements, such as school, work, marriage, peers, or a serious illness (28). The most frequently cited theory of coping is that of Lazarus (1991), which defines coping as cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are assessed as exceeding a person's resources. Coping is a process that leads to adaptation in three domains: functioning at work and social life, life satisfaction and mental health. In research, parents of children with malignant diseases were most often asked what strategies they used to cope with their child's illness or how they dealt with day-to-day problems and stress in the child's treatment process (11). Coping strategies are categorized in several ways: emotion-focused strategies versus problem-oriented strategies; avoidance strategies versus access strategies; strategies of repression versus sensitization; engagement strategies versus distancing (11).

From the literature, we single out another set of strategies which includes seven strategic clusters: focusing on the current problem; palliative response pattern; avoiding; passive behavior, expression of emotions, comforting cognition, and seeking social support (44). The best-described, consistent strategies were adopted by Sloper in 2000. She describes five types of coping strategies: problem-solving; self-directed strategies; support seeking; wishful thinking and distancing (45). Coping using the strategy of "wishful thinking" is somewhat vague. According

to Patterson et al. (2004), parents most often use 3 strategies for coping with a child's illness.

- Appraisal-focused coping behaviors; refers to the way a person thinks about stressors or circumstances that have befallen them. Parents tried to be optimistic and maintain hope during the child's illness, to believe in God, they were more focused on the present than on thinking about the uncertain future, denying the illness, looking for the positive in the experience of the child's illness.
- Problem-focused coping behaviors; making decisions important for the course of treatment, seeking information about the tumor, trying to maintain a normal family life, organization of family members, one parent quitting his/her job to be with the child.
- Emotion-focused coping behaviors; humor, fun, celebrating little success in treatment, seeking and receiving support from friends, relatives, religious communities, hiding feelings from family members as a way of coping, "parents pretending" to be stronger than they are to support other family members, diary writing (41).

The mental state of the child has a high impact on parents' coping strategies. In addition, a good coping strategy is influenced by a lower level of stress, financial security, family support and previous effective ways of coping. Useful coping strategies also include open communication, focusing on positive aspects, seeking information, seeking social support, and living life "day by day". According to the results of a study (41), the most common resources that helped parents during the diagnosis, treatment and recovery of the child are: resources from the child (maturity in coping with and accepting illness, the child's courage); family resources (support of family members, quality partnership, religiosity, the cohesiveness of family members, flexibility and open communication); communitybased resources (support from friends, peers, church believers, parents of other sick children, schools, doctors, nurses, and social workers) (41).

Early identification of parents at risk is important, in order to involve the entire support and assistance team, so as to prevent parents' psychological problems in a timely manner and help them successfully cope and adapt to the child's illness. By approaching the parent holistically, taking into account his/her

behavior, speech, movements, desires, environmental conditions, level of education, gender, defense mechanisms and perception, we can work together to make a very good plan of coping with and adapting to the child's illness, as well as coping with it during and after treatment.

## Ethical dilemmas related to the involvement of parents of children with malignant diseases in research

Due to the small number of studies involving parents of children with malignant diseases, the question arises why this is so. Is the reason in our perception of them, do we think it is better not to intrude on their intimacy or are we afraid of their reaction? What would be the optimal moment to research such a vulnerable group? Several studies have been conducted that refer to parental participation in research (46,47). A study conducted in Boston in 2012 cites a positive opinion of parents regarding research. Among 276 parents, 194 agreed to participate. 62% of parents said that their participation in the research was not disturbing at all, and 69% thought that the questionnaire was useful. The question still remains about the 30% of parents who did not participate and whether taking part in a study caused them discomfort, stress, and anger, or it was some other reason (46).

According to a retrospective study of the attitudes of parents of a child with Ewing's sarcoma after the primary interview, we can determine that parents want to participate in research more than we think. Most participants experienced the first study as a positive experience (as many as 97.5%) and they believed that their involvement in the study was beneficial to others, although some parts of the interview were painful to them. From this study, it is evident that time is a very important factor. Parents whose interval between 2 interviews was more than a year, remembered the interview as less painful. An important reason for involving parents in research is altruism, i.e., helping other parents in a similar situation (47).

Research conducted on grieving parents of children who have died also has a positive view of the need for research on them. In one such 2006 study through in-depth interviews, parents stated that a period of 6 months after the child's death was appropriate for conducting the study, while several parents stated that a period of two years after death would be

more appropriate. They stressed that the skills and compassion of the interviewer are very important to them. They considered empathy and understanding as skills. Some parents described participation in the study as a kind of therapy (47).

Recent research speaks in favor of traumatic growth, which implies positive consequences after surviving trauma. It does not develop immediately after trauma, but later, and has a long-term effect (48). Demographic characteristics such as a child's diagnosis, gender, age, income, and education do not have a significant impact on a parent's decision to participate in studies. Parental beliefs, values, and perceptions play a larger role in decisions to participate (49). According to the studied literature, we can observe that qualitative research on parents of children with malignant diseases in English speaking countries is the subject of constant interest (50), while in Balkan countries this is not the case.

The conclusion of this chapter is that parents of children with malignant diseases should be included in studies, not protected from them, because ultimately the results of studies can be an important resource for health professionals and others involved in generating new and improving existing forms of psychological care, and support to parents and families as a whole. We can rule out the ethical question of whether parents should participate in studies or not and turn to the ethical approach, timing and manner of conducting studies with such a group of parents. Parents of sick children in different stages of the disease may react differently, so it is necessary to determine the right time for research so as not to further traumatize the parents. By increasing the transparency of research with expert guidance, and a holistic and individual approach to parents, we can argue that we will get the answers that parents keep to themselves.

#### Conclusion

Malignant diseases in children have a special sociomedical dimension. They cause difficulties in adapting to a new life situation. They particularly affect parents, so it is extremely important to help the parents in overcoming and coping with the daily difficulties they face. Parents of children suffering from malignant diseases are faced with a difficult and stressful situation that leaves indelible consequences on them and accompanies them throughout their lives to a greater or lesser extent. These consequences can be negative, such as feelings of sadness, guilt and emptiness that accompany them through life, or positive, such as understanding life as a gift from God and rejoicing in everyday "little" things.

Various professional support programs for parents of seriously ill children in health care institutions across Europe and the world have proven to be a good practice. Some hospitals, e.g., in the United States, have specifically designed interventions and specially trained health professionals of all profiles who can be made available to parents in 24 hours. Based on various studies of parents whose children have had malignant diseases, they have developed good methods of communication, approaches to parents and children, techniques for communicating bad news and skills to support parents. Going through the various phases - from getting the diagnosis, through treatment to the end of treatment, parents encounter various difficulties in which the medical staff can greatly help them. Proper access to communication can facilitate, and in some cases prevent, the difficulties that parents typically face.

In addition to the health care system, the educational and social care systems, as well as the legal system, also have their shortcomings, which they should work on in order to be supportive of parents, and not be an obstacle and an additional burden. Unless we have experienced a particular trauma, we cannot imagine all the emotional turbulence and difficulties that parents go through, but that is why we can be their support and partners in the process of treating a child, which is very important to them. It means a lot to them to feel that they are not alone and abandoned in health care and other systems.

Given the literature studied, we can conclude that we should not be afraid of parental reactions during the treatment of their child, nor should we be afraid to ask them about their condition, needs and difficulties. The vast majority of parents need psychological help and support, advice and guidance, and the opportunity to express their difficulties to health care professionals. Only continuous research on the needs and problems of parents can make life's difficult moments easier for parents.

## References

- Maligne bolesti u djece u Republici Hrvatskoj. Hrvatski zavod za javno zdravstvo; 2019. Available from: https://www.hzjz.hr/wp-content/uploads/2021/12/ Bilten44\_2019.pdf Accessed: 19.04.2022. Croatian.
- Knops RR, Hulscher ME, Hermens RP, Hilbink-Smolders M, Loeffen JL, Kollen WJ, et al. High-quality care for all children with cancer. Ann Oncol. 2012;23(7):1906-11.
- Kazak AE, Barakat LP. Brief report: parenting stress and quality of life during treatment for childhood leukemia predicts child and parent adjustment after treatment ends. J Pediatr Psychol. 1997;22(5):749-58.
- Sagadiyeva M. The Difficulties Experienced by the Parents of Children with Cancer. Research & Reviews: Journal of Medical and Health Sciences. 2021; 10(2):11-4.
- Kazak AE, Alderfer M, Rourke MT, Simms S, Streisand R, Grossman JR. Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. J Pediatr Psychol. 2004;29(3):211-9.
- Barrera M, D'Agostino NM, Gibson J, Gilbert T, Weksberg R, Malkin D. Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. Psychooncology. 2004;13(9):630-41.
- 7. Miller GE, Cohen S, Ritchey AK. Chronic psychological stress and the regulation of pro-inflammatory cytokines: a glucocorticoid-resistance model. Health Psychol. 2002;21(6):531-41.
- Frank NC, Brown RT, Blount RL, Bunke V. Predictors of affective responses of mothers and fathers of children with cancer. Psychooncology. 2001;10(4):293-304.
- Barakat LP, Kazak AE, Meadows AT, Casey R, Meeske K, Stuber ML. Families surviving childhood cancer: a comparison of posttraumatic stress symptoms with families of healthy children. J Pediatr Psychol. 1997;22(6):843-59.
- Kazak AE, Boeving CA, Alderfer MA, Hwang WT, Reilly A. Posttraumatic stress symptoms during treatment in parents of children with cancer. J Clin Oncol. 2005;23(30):7405-10.
- 11. Norberg AL, Lindblad F, Boman KK. Parental traumatic stress during and after paediatric cancer treatment. Acta Oncol. 2005;44(4):382-8.
- 12. Grootenhuis MA, Last BF. Predictors of parental emotional adjustment to childhood cancer. Psychooncology. 1997;6(2):115-28.
- 13. Džombić A, Kecman Ž, Ogresta J. Poteškoće s kojima se susreću roditelji za vreme lečenja deteta od maligne bolesti. 6 ICCCPO Regionalna konferencija Udruženja roditelja dece obolele od malignih bolesti. Beograd; 2012. Serbian.

- Pelcovitz D, Goldenberg B, Kaplan S, Weinblatt M, Mandel F, Meyers B, et al. Posttraumatic stress disorder in mothers of pediatric cancer survivors. Psychosomatics. 1996;37(2):116-26.
- 15. Greenberg H, Meadows A. Psychosocial impact of cancer survival on school-age children and their parents. Psycho-Oncology. 1991;9(4):43-56.
- Boman K, Lindahl A, Björk O. Disease-related distress in parents of children with cancer at various stages after the time of diagnosis. Acta Oncol. 2003;42(2):137-46.
- 17. Aitken TJ, Hathaway G. Long distance related stressors and coping behaviors in parents of children with cancer. J Pediatr Oncol Nurs. 1993;10(1):3-12.
- 18. Vance YH, Morse RC, Jenney ME, Eiser C. Issues in measuring quality of life in childhood cancer: measures, proxies, and parental mental health. J Child Psychol Psychiatry. 2001;42(5):661-7.
- 19. Kupst MJ, Natta MB, Richardson CC, Schulman JL, Lavigne JV, Das L. Family coping with pediatric leukemia: ten years after treatment. J Pediatr Psychol. 1995;20(5):601-17.
- Sawyer MG, Streiner DL, Antoniou G, Toogood I, Rice M. Influence of parental and family adjustment on the later psychological adjustment of children treated for cancer. J Am Acad Child Adolesc Psychiatry. 1998;37(8):815-22.
- 21. Kubler-Ross E. O smrti i umiranju. Zagreb: MISL; 2008. Croatian.
- 22. Lewandowska A. The Needs of Parents of Children Suffering from Cancer-Continuation of Research. Children (Basel). 2022;9(2):144.
- 23. Martinson IM, Cohen MH. Themes from a longitudinal study of family reactions to childhood cancer. Psycho-Oncology. 1988;6(3-4):81-98.
- 24. Kreitler S, Weyl Ben Arush M. Psychosocial aspects of pediatric oncology. England: John Wiley & Sons; 2004.
- 25. Glover DA, Poland RE. Urinary cortisol and catecholamines in mothers of child cancer survivors with and without PTSD. Psychoneuroendocrinology. 2002;27(7):805-19.
- 26. Đorđević V, Braš M, Brajković L. Palijativna skrb: mostovi nade i čovječnosti. Zagreb: Roketa; 2012.
- 27. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-11.
- 28. Bearison DJ, Mulhern, RK. Pediatric Psychooncology. New York: Oxford University Press; 1994.
- 29. Coyne IT. Parental participation in care: a critical review of the literature. J Adv Nurs. 1995;21(4):716-22.
- 30. Bragadóttir H. A descriptive study of the extent to which self-perceived needs of parents are met in paediatric units in Iceland. Scand J Caring Sci. 1999;13(3):201-7.
- Shields L, Kristensson-Hallström I. We have needs, too: Parental needs during a child's hospitalisation.

- OBIN. 2004;3(3):1-23.
- 32. Norberg AL, Steneby S. Experiences of parents of children surviving brain tumour: a happy ending and a rough beginning. Eur J Cancer Care (Engl). 2009;18(4):371-80.
- 33. Palmer SL, Lesh S, Wallace D, Bonner MJ, Swain M, Chapieski L, et al. How parents cope with their child's diagnosis and treatment of an embryonal tumor: results of a prospective and longitudinal study. J Neurooncol. 2011;105(2):253-9.
- 34. Meert KL, Schim SM, Briller SH. Parental bereavement needs in the pediatric intensive care unit: review of available measures. J Palliat Med. 2011;14(8):951-64.
- 35. van Staa A, Jedeloo S, van der Stege H; On Your Own Feet Research Group. "What we want": chronically ill adolescents' preferences and priorities for improving health care. Patient Prefer Adherence. 2011;5:291-305.
- 36. Kazak AE. Surviving cancer competently intervention program-newly diagnosed. The Children's Hospital of Philadelphia; 2004.
- McGrath P. Identifying support issues of parents of children with leukemia. Cancer Pract. 2001;9(4):198-205.
- 38. Norberg AL. Burnout in Mothers and Fathers of Children Surviving Brain Tumor. J clin psychol med. 2007;14(2):130-7.
- 39. Woznick LA, Goodheart CD. Living with childhood cancer. APA Life Tools. Washington: American Psychological Association; 2009.
- 40. Baraban D, Mandić Z, Majdanžić M. Stupanj zadovoljstva roditelja bolničkom skrbi djece. Pediatr Croat. 2004;48(3):1 7. Croatian.
- 41. Patterson JM, Holm KE, Gurney JG. The impact of child-hood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. Psychooncology. 2004;13(6):390-407.

- 42. Hegeduš Jungvirth M, Grgurić J. Dnevne bolnice u pedijatriji današnja svjetska iskustva. Paediatr Croat. 2007 51(2):1-9. Croatian.
- 43. Meert KL, Eggly S, Pollack M, Anand KJ, Zimmerman J, Carcillo Jet al; National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. Pediatr Crit Care Med. 2008;9(1):2-7.
- Hoekstra-Weebers JE, Jaspers JP, Kamps WA, Klip EC. Psychological adaptation and social support of parents of pediatric cancer patients: a prospective longitudinal study. J Pediatr Psychol. 2001;26(4):225-35.
- 45. Sloper P. Predictors of distress in parents of children with cancer: a prospective study. J Pediatr Psychol. 2000;25(2):79-91.
- 46. Olcese ME, Mack JW. Research participation experiences of parents of children with cancer who were asked about their child's prognosis. J Palliat Med. 2012;15(3):269-73.
- 47. Hynson JL, Aroni R, Bauld C, Sawyer SM. Research with bereaved parents: a question of how not why. Palliat Med. 2006;20(8):805-11.
- 48. Price J, Jordan J, Prior L, Parkes J. Comparing the needs of families of children dying from malignant and non-malignant disease: an in-depth qualitative study. BMJ Support Palliat Care. 2012;2(2):127-32.
- 49. Wiley FM, Ruccione K, Moore IM, McGuire-Cullen P, Fergusson J, Waskerwitz MJ, et al. Parents' perceptions of randomization in pediatric clinical trials. Children Cancer Group. Cancer Pract. 1999;7(5):248-56.
- 50. Eiser C. Beyond survival: quality of life and follow-up after childhood cancer. J Pediatr Psychol. 2007;32(9):1140-50.

## POTREBE I POTEŠKOĆE RODITELJA DJECE OBOLJELE OD MALIGNIH BOLESTI

## Sažetak

Maligne bolesti jedan su od vodećih uzroka smrti djece u razvijenim zemljama, iako konstantan napredak u liječenju kontinuirano umanje smrtnost. Dijagnoza maligne bolesti znatan je stresor u životu djeteta i njegove obitelji te bitno mijenja kvalitetu života cijele obitelji. Predstavlja prototip stresne situacije i bolesti s potencijalno razarajućim efektima na dijete i njegovu obitelj. U ovom radu obrađeno je 50 stručnih i znanstvenih radova koji istražuju potrebe i poteškoće roditelja djece oboljele od malignih bolesti objavljenih u razdoblju između 1993. i 2022. Pravilna procjena problema i potreba s kojima se susreću roditelji djece oboljele od malignih bolesti presudna je za pružanje prikladne pomoći i skrbi. Za roditelje dijagnoza maligne bolesti njihova djeteta predstavlja psihološki i egzistencijalni izazov. Da bi potrebe roditelja bile zadovoljene, a njihove poteškoće olakšane, potrebno je nastaviti istraživanja koja uglavnom podupiru i sami roditelji kako bi im se u budućnosti olakšao taj iznimno stresan i težak dio života.

**Ključne riječi:** maligne bolesti djece, zadovoljstvo roditelja, potrebe roditelja, poteškoće, hospitalizacija, etika