

Evaluation of the Effect of Cognitive Behavioral Interventions on the Emotional Reactions of Parents of Children with Retinoblastoma

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ABSTRACT

Background: Retinoblastoma is the most common primary intraocular malignancy in childhood. Diagnosis of the disease and treatment decisions put a lot of stress on the family. Excessive anxiety and stress can lead to serious psychological problems. The cognitive behavioral approach focuses on the individuals' thoughts, behaviors, and emotions and their interaction. This study aimed to investigate the effect of cognitive behavioral interactions on the emotional reactions of parents of children with retinoblastoma.

Methods: This study was carried out using a quasi-experimental design on 106 parents of children with retinoblastoma referred to the Farabi Eye Hospital, Tehran, Iran, between 2017 and 2018. Cognitive behavioral therapy was performed through eight sessions of 90-minute training for parents. The data collection method was self-responding using the depression, anxiety, and stress scale-21 Items (DASS-21) questionnaire. Pre-and post-intervention test scores were collected for statistical analysis.

Results: The mean anxiety score decreased from 13.65 (moderate anxiety) before the cognitive-behavioral intervention to 10.13 (mild anxiety) after the intervention ($p < 0.05$). The mean depression score decreased from 11.26 (mild depression) before the intervention to 8.32 (no depression) after the intervention ($p < 0.05$). The mean stress score decreased from 10.79 (normal) before the intervention to 8.25 (normal) after the intervention ($p < 0.05$).

Conclusion: Our study showed that the occurrence of retinoblastoma in children poses a significant risk to the mental health of their parents. Cognitive-behavioral interventions can be effective in improving the level of parent's anxiety, depression, and stress.

Blindness and low vision are important health, economic, and social issues in developing and developed countries [1]. Childhood cancers are among the most important childhood diseases because of their high impact on the lives of children and the family

[2]. Retinoblastoma is the most common malignant intraocular tumor in children and is diagnosed in 90% of the cases before the age of three. In the United States, the incidence rate of retinoblastoma is 1 in 14,000-20,000 live births [3]. With earlier diagnosis and more effective

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treatments, the prognosis of the disease is promising [4]. However, being diagnosed with a chronic disorder puts a lot of pressure on the family. Parents' reactions to this disease-related crisis can be very complicated. Under the influence of the beliefs of the parents and the impact of their environment, these reactions vary widely. Parents may tend to deny the existence of the disease and may not cope with it successfully [5].

The crisis caused by the diagnosis of childhood cancer and the hospitalization of the child negatively affects all the family members [6]. This disease-related crisis may cause serious mental health problems such as anxiety, stress, and depression for the parents. The type and level of mental disorder may vary between parents. Moreover, the parents may behave differently in response to the problem, as both personal and environmental factors can directly impact their condition [7]. Social support has the potential to reduce mental issues [8]. The cognitive behavioral approach focuses on the thoughts, emotions, and behavior of the individuals. The ways we think, feel, and act are interconnected and are not separable. Cognitive behavioral therapy emphasizes changing the thinking and behavioral patterns of the patients in problematic situations. Cognitive-behavioral intervention is one of the most successful interventions in emotional disorders [9].

Anxiety, stress, and depression can have devastating impacts on the quality of life of the parents of children with chronic illnesses. As most of the parents do not seek therapy for their mental problems, emotional support plans for the family, educational sessions to teach the parents problem-solving strategies to assist them in coping with their situation, and efforts to make changes in thinking patterns and irrational beliefs of the parents could be very beneficial. The aim of this study was to evaluate the effect of cognitive behavioral interventions on the emotional reactions of the parents of children with retinoblastoma. The results of this research can be used for planning and prioritization of mental health interventions for the parents of children with chronic diseases.

Methods

The present study was a quasi-experimental research. The 106 study participants were randomly selected from the parents of children with retinoblastoma referred to the oncology operating room of Farabi Hospital, Tehran,

Sessions 1	Introduction; describing the research objectives, study intervention, and data collection method; obtaining informed consent from the participants; and taking the pre-tests.
Sessions 2	Trust building; discussion on the feelings, emotions, thoughts and concerns of the parents; communication with and motivation of the parents to complete the full training course.
Sessions 3	Discussion on the importance of mental health; threats to mental health; the importance of parental mental health during the children's treatment course.
Sessions 4	An overview on retinoblastoma and the economic, social, physical, and psychological burden of the disease.

Iran, between October 2017 and November 2018. The study was approved by the research ethics committee at the Islamic Azad University of Medical Sciences.

We studied the parents of children with a definite diagnosis of retinoblastoma. We included parents who were aware of their child's illness, had good physical health, were willing to participate in the study, and were able to read, write, and communicate in Persian. Written informed consent was obtained from parents to participate in this study. Parents who withdrew their consent or whose child died during the study were excluded.

The data collection was performed through a self-administered questionnaire. Parents completed the simple (21-item) version of the questionnaire on the depression, anxiety, and stress scale (DASS-21), which was first created by Lovibond et al in 1995 [10-11]. DASS-21 contains seven questions for each of the three variables of stress, anxiety, and depression. This 21-item questionnaire is a four-choice Likert scale, scoring from zero to three. They found that a three-factor (depression, anxiety, and stress) model provides the best fit for the DASS data following an exploratory factor analysis [12]. The validity and reliability of the DASS-21 questionnaire in Iranian patients has been studied by Samani and Jokar in 2007. The validity coefficients for the stress, depression, and anxiety factors were 0.80, 0.81, and 0.78, respectively. The validity coefficient for the whole DASS-21 test was 0.82. In addition to the retest method, the alpha validity coefficient was used to examine the internal consistency. The alpha validity coefficients for the stress, depression, and anxiety factors were 0.87, 0.75, and 0.85, respectively. In addition to the factor analysis, the general health questionnaire (GHQ) and the mental health questionnaire (MHQ) confirmed its validity [13]. The questionnaires were to be explained by and completed in the presence of an ophthalmologist, an oncologist, and a family counselor. Parents were referred to a psychiatrist in cases where the test results showed high levels of anxiety and depression.

Cognitive Behavioral Therapy Sessions

The intervention was performed through eight sessions of 90-minute training for parents of children with retinoblastoma. The pre-test was performed in the first session and the post-test was taken one month after the eighth training session.

Sessions 5	Defining the concepts of depression, stress, and anxiety; describing the physical and psychological effects of depression, stress, and anxiety on children and parents; the potential of cognitive behavioral interventions to alleviate depression, stress, and anxiety.
Sessions 6	A brief review of the previous sessions; describing the relationship between the disease, negative thoughts, and worsening of stress and anxiety.
Sessions 7	Discussion on the importance of positive attitude and logical thinking; problem-solving skills, the relationship between automated negative thoughts and depression; improving parents' skills in applying positive attitudes, according to the Beck's cognitive model; changing negative thoughts to positive thoughts based on the Meichenbaum model for stress management.
Sessions 8	Discussion on the general feelings of the parents before and after the sessions; summary of the content; practicing relaxation techniques such as deep breathing and meditation; acknowledgment of participants; and taking the post-tests.

Sample Size and Statistical Analysis

The sample size was determined based on the following formula:

$$\begin{aligned} \alpha &= 0.05\% & 1-\alpha/2 &= 0.975 \\ \beta &= 0.20\% & Z(1-\alpha/2) &= 1.96 \\ P_0 &= 0.79\% & Z(1-\beta) &= 0.84 \\ P_1 &= 0.54\% & n &= 52 \\ n_1/n_2 &= 1 \end{aligned}$$

$$n = \frac{(Z_{1-\alpha/2} - Z_{1-\beta})^2 (P_1(1 - P_1) + P_2(1 - P_2))}{(P_1 - P_2)}$$

We estimated that 106 parents are needed to be evaluated for the main outcome of this study, with an α level of 0.05 and a statistical power of 0.80.

According to the objectives of the research, descriptive statistics (frequency distribution, mean, and standard deviation) and inferential statistics (paired t-test, independent t-test, and analysis of variance (ANOVA) test) were investigated. All analyses were conducted using SPSS 24 software.

Results

The demographics of the study participants are provided in (Table 1). Equal numbers of fathers and mothers were included in this study ($n=53$). Most of the patients aged between 31 and 40 (59.43% of the participants; 29/53 fathers and 34/53 mothers) and had at least high school education (57.55% of the participants; 30/53 fathers and 31/53 mothers).

Table 1-Demographics of the study participants

	Fathers (n= 53)	Mothers (n= 53)	Total (n= 106)
Age (years)			
11-20	0	1 (1.88)	1 (0.94)
21-30	8 (15.09)	14 (26.41)	22 (20.76)
31-40	29 (54.71)	34 (64.15)	63 (59.43)
41-50	15 (28.30)	4 (7.54)	19 (17.93)
51-60	1 (1.88)	0	1 (0.94)
Educational status			
Undergraduate	23 (43.39)	22 (41.50)	45 (42.45)
Highschool diploma	16 (30.18)	19 (35.84)	35 (33.02)
Associate's degree	6 (11.32)	6 (11.32)	12 (11.32)
Bachelor's degree	7 (20.13)	6 (11.32)	13 (12.26)
Master' degree	1 (1.88)	0	1 (1.89)
Occupational status			
Working	41 (77.35)	6 (11.32)	47 (44.34)
Housekeeper	0	33 (62.26)	33 (31.13)
Retired	1 (1.88)	1 (1.88)	2 (1.89)
Unemployed	11 (20.75)	13 (24.52)	24 (22.64)

DASS-21 scores

The DASS-21 test scores are provided in Table 2. There were significant differences between the mean scores of

anxiety, stress, and depression in both fathers and mothers before and after the cognitive behavioral therapy.

Table 2-DASS-21 scores pre- and post-therapy

		Pre-intervention	Post-intervention	P value
Anxiety	Fathers	12.47±5.2	9.47±4.79	0.002
	Mothers	14.26±4.78	10.79±5.29	0.001
	Total	13.65±4.99	10.13±5.04	0.001
Stress	Fathers	10.04±5.96	7.53±5.11	0.022
	Mothers	11.55±5.61	8.98±5.31	0.017
	Total	10.79±5.79	8.25±5.21	0.020
Depression	Fathers	10.74±6.06	7.96±5.33	0.014
	Mothers	11.78±5.85	8.68±5.67	0.007
	Total	11.26±5.95	8.32±5.50	0.001

Overall, the mean parental depression score significantly decreased from 11.26±5.95 before the intervention to 8.32±5.50 after the intervention ($p<0.001$). The mean parental anxiety score significantly decreased from 13.65±4.99 before the cognitive behavioral intervention to 10.13±5.04 after the intervention ($p<0.001$). The mean parental stress score significantly decreased from 10.79±5.79 before the intervention to 8.25±5.21 after the intervention ($p<0.001$).

Discussion

Many therapeutic and educational interventions have been experimentally validated for mood, anxiety, and stress disorders. The aim of this study was to investigate the effect of cognitive behavioral interventions on the emotional reactions of parents of children with retinoblastoma. The present study showed statistically significant differences in the levels of depression, anxiety, and stress before and after the educational intervention. These results demonstrate the effectiveness of cognitive behavioral interventions in reducing the severity of the mental health problems in parents of children with retinoblastoma.

Rostamali et al. (2017) examined the quality of life and emotional reactions in patients undergoing enucleation surgery. The results showed that there were increased levels of stress, anxiety, and depression in patients after enucleation, and most of the patients were found to have a poor quality of life [14]. Farhangi et al. (2016) examined the levels of depression, anxiety, and stress in parents of children with leukemia. They found the rate of patients with abnormal stress level to be 37%, abnormal anxiety level to be 79%, and abnormal depression level to be 67%. These found no relationship between these variables and the participant's age, sex, and duration of the illness. Accordingly, the authors concluded that parental mental health should be monitored closely during the treatment of children with serious illnesses [15]. Mami et al. (2016) examined the effectiveness of behavioral therapy on the symptoms of depression, anxiety, and stress in four patients with anorexia nervosa. They found that dialectical behavior therapy can

considerably reduce the depression, anxiety, and stress in these patients [16].

Mami and Amirian (2015) evaluated the effects of cognitive behavioral therapy on the mental health of mothers of children with autism. Forty mothers were randomized into two groups of 20 mothers each; the control and the behavioral therapy for 10 sessions, 20 hours collectively. They found a significant difference between the control and intervention groups in mental health scores and inferred that cognitive behavioral intervention would be beneficial for mothers of children with autism [17]. Oraki et al. (2015) evaluated the effectiveness of cognitive behavioral intervention on the mental health of infertile women. In this study, ten sessions of anger management therapy significantly improved the mental health of patients [18].

Enrique et al. (2017) reported the psychosocial facilitating factors and barriers impacting the decision of parents of children with retinoblastoma to give consent for a potentially lifesaving enucleation surgery. According to the authors, the awareness of cancer as a fatal disease is among the main barriers, while the appreciation of the value of life and the efficacy of treatments are favorable factors [19]. Hence, therapy sessions can potentially help the parents in the decision-making process for their children. Hamama-Raz et al. (2012) explored the emotional sensitivity of parents of children with retinoblastoma. They observed that parents could have unstable emotional states during the time period between the diagnosis of the disease in their children and after their discharge from the hospital after enucleation. They have concluded that parents of children with retinoblastoma need multidisciplinary support during this time interval [20]. Farahani et al. (2017) investigated the effect of maternal narrative writing on depression, anxiety, and stress. They collected data from 62 mothers of children with stem cell transplantation using the DASS-21 questionnaire and found narrative writing to be a simple and cost-effective intervention for mothers of children with a critical illness [21].

Collins et al. (2019) examined the level of depression, anxiety, and stress in parents of children with retinoblastoma. Their findings showed depression, stress, and anxiety in the majority of parents [22]. Willard et al.

(2017) evaluated parental stress in parents of children with retinoblastoma. Based on their findings, parental stress can significantly affect child functioning [23]. Gelkopf et al. (2019) examined the association between distress of parents of retinoblastoma children and perceived health literacy and self-efficacy. They found that self-efficacy can prevent parental depression and anxiety [24]. By assessing the lived experience of 11 parents, Beddard et al. (2019) found numerous difficulties for the parents of children who have had retinoblastoma and highlighted the benefits of psychological and social support for them [25]. The results of these previous studies are consistent with our findings on the increased levels of depression, anxiety, and stress in parents of children with retinoblastoma. Herein, we demonstrated that cognitive-behavioral interventions could alleviate these complications. Following therapy sessions, we observed significantly reduced levels of depression ($p=0.001$), anxiety ($p=0.001$), and stress ($p=0.020$) in the parents of children with retinoblastoma.

Cognitive behavioral therapy is an effective, non-invasive, and low-cost psychosocial intervention. This short-term talking therapy can improve the ability of individuals to deal with their problems by changing the way they think and behave. As discussed above, the effectiveness of cognitive behavioral therapy has been established in a wide range of parental mental health problems. Promising findings of this study demonstrate the strong potential of this approach to be used in the management of mental health problems of parents of children with retinoblastoma, prevention of the mood disorders in parents of children with critical conditions, and as a basis for the health promotion planning for the parents of children with chronic diseases.

The main limitation of this study was the poor psychological status of the parents due to their child's illness, which impaired their ability to comprehend the study instructions and limited their availability for the therapy sessions. Moreover, an in-depth analysis of the impact of cognitive behavioral interventions on the study participants was not feasible due to the emotional problems of the participants.

Evaluation of the efficacy of other types of psychosocial interventions in the mental health problems of parents of children with retinoblastoma remains an important issue for our future studies. It would be interesting to compare the results obtained using different types of psychosocial interventions.

Our study showed that the occurrence of retinoblastoma in children poses a serious risk to the mental health of their parents. According to the results of this study, cognitive behavioral therapy can significantly improve the levels of depression, anxiety, and stress in the parents. Establishment and expansion of an emotional and psychological support center are highly recommended to

improve the mental health of parents of children with critical illnesses such as retinoblastoma.

Conclusion

Our study showed that the occurrence of retinoblastoma in children poses a serious risk to the mental health of their parents. According to the results of this study, cognitive behavioral therapy can significantly improve the levels of depression, anxiety, and stress in the parents. Establishment and expansion of an emotional and psychological support center are highly recommended to improve the mental health of parents of children with critical illnesses such as retinoblastoma.

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References

- [1] Karaolani G, Katsaros A, Palla VV, Lionaki S, Moris D, Karanikola E, et al. Urine NGAL as a biomarker of kidney damage after on- and off-pump coronary artery bypass graft surgery: a prospective pilot study. *Hellenic J Cardiol.* 2015; 56(2):160-8.
- [2] Espirito E, Gaiva M, Espinosa M, Barbosa D, Belasco A. Taking care of children with cancer: evaluation of the caregivers' burden and quality of life. *Rev. Latino-Am. Enfermagem.* 2011;19(3):515-22.
- [3] American Academy of Ophthalmology. *Ophthalmic Pathology and Intraocular Tumors. Part 4: EB (European Board)*, 2016.
- [4] Canturk S, Qaddoumi I, Khetan V, Ma Z, Furmanchuk A, Antoneli CBG et al. Survival of retinoblastoma in less-developed countries impact of socio economical and health-related indicators. *Br J Ophthalmol.* 2010; 94(11): 1432–36.
- [5] Malone CA. Observation on the role of family therapy in child psychiatric training. *J Am Acad Child Psychiatry.* 1974; 13(3):437-58.
- [6] Hockenberry MJ, Wilson D, Wong DL. *Wong's clinical manual of pediatric nursing.* Ed. 8, Mosby, 2012.
- [7] Rafei H. *Autism: An Evaluation of Dermatology.* Publications of Tehran University. 2012.
- [8] Safari G. *Let Us Have a Problem.* Ed. 6: Tolo Danesh Publications, 2011.
- [9] Corey G. *Theory and Practice of Counseling and Psychotherapy.* Ed 9: 2013.
- [10] Lovibond SH, Lovibond PF. *Manual for the Depression Anxiety Stress Scales.* Sydney: Psychology Foundation. Ed. 2: 1995.

- [11] Lovibond PF, Lovibond SH. The Structure of Negative Emotional States: Comparison of Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behav Res Ther.* 1995; 33(3):335-43.
- [12] Brown TA, Chorpita BF, Kortitsch W, Barlow DH. Psychometric Properties of Depression Anxiety Stress Scales (DASS) in Clinical Samples. *Behav Res Ther.* 1997; 35(1): 79-89.
- [13] Samani S, Jokar B. Validity and Reliability of the Short Depression, Anxiety and Stress Scale. *Shiraz University Social and Human Journal.* 2007; 26(3):65-77.
- [14] Rostamali S, Adhami Moghadam F, Sahebalzamani M. A study of Life, Self-efficacy and Emotional Reaction in patients undergoing enucleation referring to dependent Hospitals of Tehran University of Medical Sciences. *Journal of Research in Medical and Dental Sciences.* 2017; 5 (6):79-84.
- [15] Farhangi H, Moharari F, Garahi L, Arman pour P. Evaluation of stress, anxiety and depression in parents of children with leukemia: brief report. *Tehran Univ Med J.* 2017; 74(10): 741-745.
- [16] Mami S, Amirian K. The effect of cognitive-behavioral group therapy on mental health and irrational beliefs of mothers with autistic children. *Woman & Study of Family.* 2015; 8(30): 69-82.
- [17] Mami S, Ebrahimian S, Soltani S. Effectiveness of dialectic behavioral therapy on depression, anxiety and stress in anorexia nervosa disorder: four case study. *The Journal of Urmia University of Medical Sciences.* 2016; 27(5):384-92.
- [18] Oraki M, VazirNasab B, Alipour A. The Effectiveness of Anger-Based Cognitive Behavioral Intervention on the Mental Health of Infertile Women. *Urmia Medical Research Journal.* 2015; 26(8): 652-662.
- [19] Domingo RED, Toledo MSW, Mante BVL. Psychosocial Factors Influencing Parental Decision to Allow or Refuse Potentially Lifesaving Enucleation in Children with Retinoblastoma. *Asia Pac J Oncol Nurs.* 2017; 4(3):191-96.
- [20] Hamama Raz Y, Rot I, Buch binder E. The coping experience of parents of a child with retinoblastoma-malignant eye cancer. *J Psychosoc Oncol.* 2012; 30(1):21-40.
- [21] Farahani H, AfshariAzad S, Sahebalzamani M. Investigation the Effect of Maternal Narrative Writing on Depression, Anxiety and Stress in Pediatric Stem Cell Transplantation. *NeuroQuantology.* 2017; 15(4):56-62.
- [22] Collins MLZ, Bregman J, Ford JS, Shields CL. Depression, Anxiety, and Stress in Parents of Patients with Retinoblastoma. *Am J Ophthalmol.* 2019; 207:130-43.
- [23] Willard VW, Qaddoumi I, Zhang H, Huang L, Russell KM, Brennan R, et al. A longitudinal investigation of parenting stress in caregivers of children with retinoblastoma. *Pediatr Blood Cancer.* 2017; 64(4):10.1002/pbc.26279.
- [24] Gelkopf MJ, Chang TE, Zhang Y, Zhang C, Yi K, Fang V, et al. Parental coping with retinoblastoma diagnosis. *J Psychosoc Oncol.* 2019;37(3):319-34.
- [25] Beddard N, McGeechan GJ, Taylor J, Swainston K. Childhood eye cancer from a parental perspective: The lived experience of parents with children who have had retinoblastoma. *Eur J Cancer Care (Engl).* 2020; 29(2):e13209..