

Hope, Depression, Anxiety and Associated Factors Among Parents of Retinoblastoma Patients During the Pneumonia Epidemic in COVID-19: A Cross-Sectional Study

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Research article

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Abstract

Background

The 2019 coronavirus disease (COVID-19) is a global public health emergency. So far, only a limited number of studies have investigated the impact of the pneumonia pandemic in COVID-19 on the mental health of parents having children with cancer. This study investigated the hope, depression, anxiety, and relevant influencing factors among parents of retinoblastoma patients during the pneumonia epidemic in COVID-19.

Methods

A total of 317 parents having children with retinoblastoma admitted to the Ninth People's Hospital affiliated with the Shanghai Jiao Tong University, School of Medicine, and Qilu Children's Hospital of Shandong University were investigated by cross-sectional investigation and convenient sampling. The survey tools included a Demographic Questionnaire, Herth Hope Index (HHI), The Generalized Anxiety Disorder (GAD-7), and The Patient Health Questionnaires (PHQ)-2.

Results

The hope level score of the parents of retinoblastoma patients was (35.36 ± 4.42) , which was at the medium level. The highest dimension of the hope score was to take positive action (12.07 ± 1.57) , and the lowest dimension was to maintain a close relationship with others (11.50 ± 1.64) . The incidence rates of anxiety and depression were 41.32% (131/317) and 29.97% (95/317), respectively. Hope level was negatively correlated with anxiety and depression. Monoculus or binoculus disease, sleep quality, health status, having anxiety/depression or not, had a statistically significant effect on the research subjects' hope level ($p < 0.05$). Multiple linear regression analysis revealed that the course of the disease, education level, and depression were independent influencing factors ($p < 0.05$), which could explain 22.60% of the variation in hope level.

Conclusion

During the COVID-19 outbreak, medical staff should formulate targeted intervention measures according to the different characteristics of eye disease, the course of the disease, the parents' educational level, health status, and emotional state so as to improve parents' hope level.

Background

In 2019, a novel coronavirus outbreak (COVID-19 pneumonia) first occurred in Wuhan City, Hubei Province, China, after which it quickly spread worldwide, becoming a global public health emergency according to the World Health Organization (WHO) [1, 2]. This new type of virus is highly contagious; it spreads quickly and can infect people of all ages [3]. The virus spread decreased the general public's

mental health and increased anxiety and depression. In addition, sleep quality decreased in many individuals [4, 5].

WHO advocates social isolation and self-isolation [6]. Many provinces in China have taken measures to restrict travel and personnel mobility, which has affected the treatment and re-examination of cancer patients to a certain extent. Family caregivers (FCS) of cancer patients face unprecedented uncertainty and are prone to depression, especially under the double threat of disease and panic [7]. A total of 17.7% of caregivers of tumor patients have been reported to have suicidal ideation, while 2.8% have attempted suicide over the past year [8]. Moreover, the mortality rate of tumor patients' caregivers increased by 63% within five years [9]. FCS of tumor patients need to be concerned, especially the parents of children with the tumor.

Retinoblastoma (RB) is the most common primary intraocular malignant tumor in children, which leads to decreased visual function and can be life-threatening. It also brings economic burden and mental stress to society and the whole family. Parents of children with cancer are often confronting uncertainty, anxiety, stress, and feeling out of control; thus, hope is very important to these parents [10]. Parents' hope may greatly improve children's quality of life [11], treatment effect [12], and reduce the parents' psychological pain and poor adaptation after a cancer diagnosis [13]. Hope is an important coping mechanism, a fundamental source of parents' strength, and parents' inner psychological power that drives them to give continuous care [14, 15]. It is a positive driving force that influences a person's behavior and way of doing things. It can also improve confidence and courage [16].

At present, most research on childhood cancer focuses on the negative impact of cancer while ignoring parents' attitudes and behaviors who actively seek to fight cancer. While it is ever more obvious that hope can affect health, existing studies on hope mainly focus on cancer patients and terminally ill patients during chemotherapy. The purpose of this study was to investigate the hope, depression, anxiety among parents of retinoblastoma patients during the COVID-19 pneumonia epidemic and explore the influencing factors so as to provide theoretical support for the development of intervention programs that could be used in the future to improve the hope level of parents of patients with RB.

Methods

Participants

In this study, a cross-sectional and descriptive correlation design was adopted. Parents of RB patients who were treated in the Ninth People's Hospital affiliated with the Shanghai Jiao Tong University, School of Medicine and Qilu Children's Hospital of Shandong University (only the father or mother of each child's family was investigated) were recruited as research subjects. Inclusion criteria were following: (a) the parent participating is the primary caregiver of the child; (b) volunteered to participate in the survey; (c) over 18 years of age; (d) be conscious and have a certain reading comprehension ability; (e) no cognitive impairment or other mental and psychological diseases now and before; (f) no major psychological trauma over recent days. Exclusion criteria were: (a) children with RB with an advanced stage and/or are

receiving palliative care; (b) children with RB having other serious diseases; (c) children with RB who died when the study started.

Data collection

On March 9th, 2020, the research team members published a job advertisement, which included a welcome message (introducing the purpose and significance of the survey) and a link to an online questionnaire (<https://www.wjx.cn>). The online link to the questionnaire was published on WeChat. All subjects who were willing to participate in the survey filled out and submitted the questionnaire online. The investigators recycled the questionnaire through the background of the Inquirer. The survey was confidential and anonymous. The introduction part of the questionnaire explained the purpose, significance, and ways to fill out the survey. The recruitment process lasted until June 1st, 2020. A total of 320 subjects were invited to participate in the study, and 3 subjects refused. Finally, 317 valid questionnaires were collected, and the effective recovery rate was 99.06%.

Questionnaires

Demographic Questionnaire

This self-report questionnaire was designed by the authors and included the child's age, gender, tumor stage, disease course, etc.; the patient's father or mother's age, marital status, education level, etc.

Herth Hope Index (HHI)

The scale was designed by American scholar Herth *et al.* The internal consistency was 0.89 to 0.97, and a test-retest reliability coefficient was 0.91 for a variety of adult patient populations [17]. We used the Chinese version edited by Zhao and Wang Jian [18]. HHI (range 12–48) is a self-report scale consisting of 12 items, including 4 reaction categories (1 = strongly disagree to 4 = strongly agree) to evaluate the level of hope. Scores were divided into 0 level (low) (12 < HHI < 36), 1 level (medium) (36 < HHI < 42), 2 level (high) (42 < HHI < 48) [19, 20]. Higher HHI scores indicated a higher level of hope [17]. The Herth Hope Scale has been shown to have satisfactory reliability and validity in different Chinese samples [21, 22], in family caregivers of patients with cancer [23] and in the general population [24].

The Generalized Anxiety Disorder (GAD-7)

GAD-7 [25] is a practical self-reported anxiety questionnaire, which has been proven to effectively assess the anxiety symptoms and severity of the general population in primary health care. This scale has good reliability and validity [26-28].

Patient Health Questionnaires-2 (PHQ-2)

PHQ-2, extracted from 9 items of the Patient Health Questionnaire (PHQ-9), is a 4-point system, ranging from 0 (not at all) to 3 (almost every day) [29]. It evaluates the frequency of "feeling down, depressed or

hopeless" and "little interest or pleasure in doing things" experienced over the past 2 weeks. The total score ranges from zero to six points, and more than three points indicate depression. We used PHQ-2 to investigate the symptoms of depression. PHQ-2 has been validated and used in China [30, 31].

Statistical analysis

The data were analyzed using SPSS 25.0 with a significance level of 0.05. Descriptive statistics were used to describe the demographic and the clinical characteristics of samples to suit the measurement level (mean \pm standard deviation for continuous variables and number and percentage (n, %) for other categorical variables). F test, T test, and Spearman correlation analysis were used to compare between groups. Through single factor analysis and correlation analysis (according to the level of $\alpha = 0.1$), the factors related to the expected score were screened out, and the multiple linear regression model was established.

Ethical considerations

The research was reviewed by the Institutional Review Board in the researcher's hospital, which is in line with the [Declaration of Helsinki](#) [32]. All the selected subjects were informed of the study's purpose, nature and were told that they could withdraw from the study at any time and were promised that their personal information would not be disclosed.

Results

Sample characteristics

The age of 317 patients with RB ranged from 1 month to 172 months, with an average age of 41.38 ± 23.14 months. Univariate analysis showed significant differences in the scores of hope level among the subjects with different eye diseases, sleep quality, health status, anxiety, and depression ($P < 0.05$, **Table 1**).

Distribution of hope level

The total score of hope level in parents of patients with Rb was 35.36 ± 4.42 . The scores of all levels and dimensions are shown in **Tables 2** and **Table 3**. Among them, 3 cases (0.95%) were of low level, 155 cases (48.90%) of medium level, and 159 cases (50.15%) of high level. The highest scored hope dimension was taking positive action, while the lowest scored dimension was keeping a close relationship with others.

Correlation between hope and emotional

There was a negative correlation between parents' hope level and anxiety and depression ($r = -0.394, -0.486$, all $p < 0.001$), as shown in **Table 4**.

Study factors associated with hope

The single factor analysis (t-test, F test) and Spearman correlation analysis were used to screen the independent variable ($\alpha= 0.1$) subsequently included in the multivariate linear regression equation. The total score of hope level was used as the dependent variable, which was inputted in the forward stepwise regression method. α_{in} of 0.05 and α_{out} of 0.1 were used to select and eliminate independent variables. The multiple linear regression model was used to examine the horizontal predictive factors for hope. The final course of the disease, education level, and depression entered the regression equation, accounting for 22.60% of the variation in the hope level, as shown in **Table 5**.

Discussion

Analysis of levels of hope among parents of RB patients during the pneumonia epidemic in COVID-19

This study showed that during the COVID-19 epidemic, the hope level of 48.90% of parents of (N=155/317) RB patients was at the middle level, while it was at low level in 0.95% of parents. By contrast, Sisk *et al* [14] reported that 55% of parents (N=206/374) had high levels of hope. The reason for this inconsistency may be the difference between the survey time and survey subjects. Our survey was conducted during the COVID-19 outbreak, and the selected research subjects were all from well-known domestic tertiary general hospitals with strong medical diagnoses and treatment levels. Second, the health condition of RB's children was not poor. In this study, 65.93% of the patients were simply reexamined or cured, and 95.58% of the patients were in the intraocular phase. The protection of eyes and eyesight was promising in most patients. Patients with unilateral RB accounted for 70.98%. A previous study reported that parents who have adapted to RB diagnosis have a higher level of hope compared to those who had difficulty adopting [33]. In this survey, 86.12% of patients experienced RB for more than six months, and their parents basically adapted to RB's diagnosis. Some scholars reported that parents defined hope as their understanding of the child's health [34]. In this study, the parents' understanding of RB accounted for 93.69%, so, most of the subjects received systematic health education and rehabilitation guidance, which was helpful to establish a correct understanding of rehabilitation and enhance confidence and belief in rehabilitation. In addition, 97.16% of the subjects were married, while only 9 were divorced or separated. Married couples cope with difficulties more easily than divorced ones.

The highest scored dimension of the hope scale was taking positive action, which indicated that the subjects rooted for the patient' rehabilitation, were willing to take active action, and were actively cooperating with doctors. The possibility of keeping a close relationship with others was the lowest scored dimension, which might be because the respondents needed to spend a lot of time taking care of their children, which affected their close relationship with others. In addition, during the investigation, the awareness of COVID-19 was increasing, and the social contacts were reduced. This suggested that attention should be paid to the subjects' social interaction in clinical nursing care, the communication and the close relationship could be fostered through the network. The more positive attitude towards the disease, the subjects were more willing to take positive actions to improve the present situation. Communication with doctors and other health care professionals could significantly increase hope levels [35]. Even if the child's prognosis is poor, doctors' disclosure of prognosis can bring hope [36]. Medical

staff should be encouraged to communicate with the parents so that they can understand the treatment, nursing, and prognosis of RB, thus stimulating realistic hope.

Higher education levels are associated with better adaptability, lower stress levels, less anxiety and depression, and keep active problem-solving methods [35]. A previous study showed that hope is associated with pain and despair but negatively with anxiety and depression [15, 37]. This study also showed that the parents' hope level of RB patients was negatively correlated with anxiety and depression. Better psychosocial and spiritual support could promote higher levels of hope [38]. Stronger family cohesion was related to higher hope and lower levels of anxiety and depression symptoms [39], as well as the quality of life in children [11]. Medical staff should try their best to identify families with poor family cohesion and encourage them to communicate with other family members, friends, medical care, and other friends through online platforms such as messages and WeChat so as to keep their hope up and optimize happiness.

Risk factors analysis of hope level during COVID-19 pneumonia epidemic in parents of RB patients

Univariate analysis showed significant differences in the scores of hope level related to monocular, sleep quality, health condition, anxiety, and depression ($P \leq 0.05$). Multiple linear regression analysis showed that the course of the disease, education level, and depression were the independent influencing factors ($p \leq 0.05$), which could explain the 22.60% of the variation in the hope level. Parents' hope is a widespread multidimensional phenomenon, and the factors hindering and promoting hope levels are related to many aspects of family life, such as the health of the patient, the parents' economic situation, beliefs, and pets [15]. Hope was negatively correlated with psychological distress and depression, and its relationship with anxiety remained unclear, which is consistent with a previous study [40].

The course of illness is negatively correlated with hope levels

The survey results showed that the disease course was a negative factor affecting the hope level of parents of patients with RB, which is consistent with Xiao *et al* [41]. The longer course of the disease was associated with longer care time. The characteristics of caring work also make caregivers live under high pressure and high load for a long time, which may easily lead to a negative attitude adopted by caregivers themselves during the rehabilitation treatment. In clinical work, medical staff should pay attention to assess the hope level of parents of patients with RB with a long course of the disease, explaining the illness, giving the information support, reducing their uncertainty and helplessness, and enhancing the hope in effectiveness of the treatment for patients.

Lower educational level is associated with a lower level of hope

Hope is a kind of attitude that people adopt when facing crises and challenges, which is closely related to the individual level of education. The survey results showed that education level was a positive factor affecting the ideal level, which is consistent with Xiao *et al* [41] and Li *et al* [42]. People with high educational levels are more likely to obtain relevant knowledge and social resources on diseases and

health, prepare psychologically and are less likely to develop negative emotions such as anxiety and depression. This also suggests that the government, the media, and medical staff should pay more attention to these groups and provide them with additional psychological support and help. For parents with low educational levels, clinical medical staff should be patient when giving education and use easy-to-understand words to guide them to cooperate and participate in treating children's diseases actively.

Depressed people had lower levels of hope compared to those who are non-depressed

The survey showed that the incidence rates of anxiety and depression of parents of children with RB were 41.32% (131/317) and 29.97% (95/317), respectively. This analysis might be due to the outbreak of the epidemic. Tumor patients are susceptible to COVID-19 because of their low immunity when they go to the hospital. The lack of necessities caused by the epidemic has led to a decline in the nutritional status of cancer patients. The suspension of production during the epidemic period further increased the economic burden of cancer patients' families. Delaying or even stopping the treatment of a tumor may lead to the tumor's progression or deterioration. Continuous assessment of spiritual needs is very important for keeping hope [16]. During the COVID-19 outbreak, 60% of caregivers with depressive symptoms complained of lacking treatment support (e.g., online or face to face) [7]. It is suggested that the public health department, psychiatry department, health care department, nursing professionals, and family members of cancer patients should establish a cooperative partnership to ensure continuous care during the unique pneumonia outbreak of COVID-19. For people with depressive symptoms, necessary psychological counseling and intervention should be promptly conducted. Internet platforms, such as WeChat were used for popular science propaganda on novel coronavirus and treatment or rehabilitation of tumor diseases to reduce patients' anxiety.

Clinical Implications

This study's results helped health care professionals develop intervention measures for mental health problems of parents of RB patients during the COVID-19 epidemic and provided a scientific basis for the establishment of an early warning system for major social stress events in the future. First, health departments need to identify high-risk groups, such as cancer patients and their families. Second, the health department should promote health science education for high-risk groups, such as focusing on easy-to-understand education for people with low education levels. Finally, online clinics for oncology and psychiatry should improve and expand during the epidemic period of infectious diseases.

Limitations

This study has a few limitations. First, the convenient sampling method was adopted in this study. The research samples come from two research centers, and RB parents with WeChat contact information could cause certain selection bias, which may affect the representation of the results to a certain extent. Future research could be conducted in multi-centers to make the research results more universal. Second, the parents' hope changed over time [43], with different levels in different periods. However, this survey was a cross-sectional survey, and a longitudinal follow-up survey is not planned. In the follow-up studies,

attention should be paid to the use of longitudinal research to understand the process of dynamic changes in hope.

Conclusions

The present survey on the impact of the novel coronavirus epidemic on families of patients with RB showed that the hope level of parents of patients with RB was in the medium range, while parents experienced different degrees of anxiety and depression. Hope level, which needs to be improved, was related to negative emotions. There is an urgent need for the implementation of hope-related assessments and intervention. However, this study showed that the course of the disease, education, and depression was particularly significant in predicting the degree of hope. The state, society, and individuals should make joint efforts to provide parents of RB patients with knowledge, attitude, and behavior intervention, and guide them in improving their hope level so as to win the psychological battle under the novel coronavirus epidemic.

Abbreviations

COVID-19: The 2019 coronavirus disease; RB: Retinoblastoma; HHI: Herth Hope Index; GAD-7: The Generalized Anxiety Disorder; PHQ: The Patient Health Questionnaires; FCS: Family caregivers; WHO: the World Health Organization

Declarations

Ethics approval and consent to participate

The research was conducted in accordance with the Declaration of Helsinki and has been approved by the ethics committee of the hospital (approval number SH9H-2019-T289-2). Participants were provided with the online information sheet first and proceeded if they agreed to participate.

Consent for publication

Not applicable.

Availability of data and materials

Data can be obtained from the corresponding author, on request.

Competing interests

The authors declare that they have no conflicts of interest.

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Authors' contributions

CZ wrote the manuscript as a first author. Professor LH and LL conceived and designed the study as corresponding authors. WC contributed to the interpretation of the analysis results and revised the manuscript. TZ was involved in the collection of the data. All authors read and approved the final manuscript.

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Tables

Table 1. Characteristics of the sample (N = 317)

Characteristics	N (%)	hope score $\bar{x} \pm s$	F-value /t-value	P-value
Time since diagnosis (month)				
≤6	44(13.88)	36.02±4.72	0.930*	0.447
6-12	65(20.50)	35.09±4.06		
12-24	102(32.18)	35.65±4.29		
24-36	75(23.66)	35.28±4.40		
37+	31(9.78)	34.23±5.14		
Child sex				
male	167(52.68)	35.06±4.94	-1.294#	0.197
female	150(47.32)	35.69±3.74		
Eye disease				
monoculus	225 70.98%	35.52±4.27	-2.303#	0.022
binoculus	9229.02%	34.97±4.76		
Stage at diagnosis				
A/B/C	15(4.73)	35.80±3.12	0.580*	0.629
D	132(41.64)	35.43±4.38		
E	156(49.21)	35.14±4.55		
Extraocular phase	14(4.42)	36.64±4.60		
Type of treatment				
4	131(41.32)	34.90±4.61	2.972*	0.053
4-6	158(49.84)	35.94±4.36		
7+	28(8.84)	34.25±3.42		
Disease state				
Under treatment	108(34.07)	34.72±4.09	1.711*	0.182
Under review	206(64.98)	35.69±4.59		
Cured	3(0.95)	35.60±7.58		

Relationship				
Mother	205 [64.67]	35.17±4.44	-1.056 [#]	0.292
Father	112 [35.33]	35.71±4.39		
Parent age				
≤29	107 [33.75]	34.64±4.33	2.129 [*]	0.121
30-35	134 [42.27]	35.74±4.66		
36+	76[23.98]	35.70±4.03		
Marital status				
Married	308 [97.16]	35.41±4.44	1.309 [*]	0.272
divorced	6[1.89]	34.83±3.71		
Separated	3[0.95]	31.33±2.52		
Education				
Less than Primary	13[4.10]	35.38±4.82		
Junior high school	101 [31.86]	34.48±4.17		
High school or technical secondary school	80[25.24]	35.85±4.25	1.656 [*]	0.160
College or undergraduate	114 [35.96]	35.68±4.66		
postgraduate	9[2.84]	36.78±4.24		
Sleep quality				
Good	61[19.24]	36.82±5.06	4.426 [*]	0.005
General	200 [63.09]	35.30±3.89		
Insomnia	22[6.94]	34.68±5.70		
Unstable sleep	34[10.73]	33.56±4.61		
Health status				
Very good	64[20.19]	36.81±4.46		
Good	139	35.35±4.42	3.637 [*]	0.013

	43.85			
General	107 33.75	34.55±4.14		
Poor	72.21	34.71±5.82		
Degree of understanding of RB				
Not at all	206.31	35.05±5.45	0.405*	0.667
Know a little	262 82.65	35.30±4.26		
Know	3511.04	35.97±5.00		
Depressive condition				
Positive	9529.97	32.59±4.05	7.993#	<0.001
Negative	222 70.03	36.55±4.03		
Anxiety condition				
Positive	131 41.32	33.79±4.55	5.566#	<0.001
Negative	186 58.68	36.47±3.98		

Note. *=F value; #=t value; N Number

Bold face p < 0.05

Tables 2. Distribution of hope level (N = 317)

Hope level	N (%)	Positive attitude [x ±s]	Positive action [x ±s]	Maintain close relationships with others [x ±s]
low level	3(0.95)	7.33±0.58	5.00±1.00	6.67±0.58
Medium level	155(48.90)	10.74±1.12	11.34±0.96	10.48±1.11
High level	159(50.15)	12.89±1.18	12.92±1.36	12.58±1.23

Tables 3. Scores and sequencing of each dimension in the hope scale (N = 317)

Dimensions	score [x ±s]	sort
positive attitudeS towards reality and the future	11.79±1.63	2
Take positive action	12.07±1.57	1
Maintain close relationships with others	11.50±1.64	3
Total score	35.36±4.42	

Table 4 Correlation between hope and emotions (N = 317)

	Total hope level score	
	r-value	p-value
Anxiety total score	-0.394	<0.001
Total depression score	-0.486	<0.001

Table 5. Multiple linear regression analysis of hope factors (N = 317)

	B-value	SE-value	β-value	t-value	p-value
Constant term	32.115	2.751	-	11.672	<0.001
course of disease	-0.041	0.017	-0.146	-2.409	0.017
Educational level	0.586	0.232	0.130	2.530	0.012
Depressive state	-3.275	0.661	-0.340	-4.955	<0.001

Note. R=0.476; R²=0.226; Adjust R²=0.185; F=5.480; p<0.001

Bold face p < 0.05