Original Article

Development and validation of psychological status questionnaire for parents of infantile hemangiomas

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Background: Infantile hemangioma (IH) is the most frequent benign tumor of infancy which impacts the psychological status of parents of affected children. Parental psychological status has a significant effect on the therapeutic effect and long-term prognosis of IH children. However, no standard questionnaires had been established previously to assess the psychological status of Chinese parents of children with IH.

Methods: This study prospectively developed and validated a psychological status instrument for the assessment of parents of patients with IH and to identify clinical features with effects on the psychological status. A total of 350 parents completed the 35-item Psychologic Status Questionnaire for parents of Infantile Hemangiomas (IH-PSQ) and provided demographic information. The IH-PSQ was refined via item analysis, validity analysis (including exploratory factor analysis and criterion-related validity) and reliability analysis (including internal consistency reliability, split half reliability, and test-retest reliability).

Results: The dimensionality of the items was evaluated using factor analysis, with results suggesting 5 factors: anxiety, depression, psychological imbalance, disease shame, and disease fear. The final instrument consists of 4 scales with a total of 23 items. Construct validity was demonstrated and IH-PSQ showed good internal coherence (Cronbach's α: 0.957), good split half reliability (0.971), and good test-retest reliability (correlation coefficient: 0.967). The correlation coefficient between the Self-Rating Anxiety Scale (SAS) and Self-rating Depression Scale (SDS) of children with IH was 0.874 and 0.754, respectively. Multiple linear regression analysis found that some characteristics will affect the score of IH-PSQ.

Conclusions: The IH-PSQ contains 5 dimensions and 23 entries, and with good reliability and validity, can objectively and effectively evaluate the psychological status of IH parents. Certain clinical characteristics of IH families, including parents' own factors (including their monthly income and cultural level) and disease-related factors of affected children (including the duration of illness, tumor size, with or without complications, single or multiple, whether being treated or not), were associated with a greater impact on IH-PSQ.

Keywords: Infantile hemangioma (IH); questionnaire; psychological status; validation; impact

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Introduction

Infantile hemangioma (IH) is one of the most common benign tumors in infants, the incidence of which can reach 4–5% (1). It is mostly located on the face and neck (2,3), and has a specific natural course, including a stage of hyperplasia, regression, and extinction. Some IHs are self-limiting and require no specific treatment (4). However, professor Jinzhe Zhang, one of the founders of China's first pediatric surgery department (5), repeatedly emphasized that the management of IH was prone to overtreatment, as most of the treatment rendered did not take the natural course of the disease into consideration (6). Many authors have labeled the overtreatment of IH as unnecessary (7-9). However, these authors have tended to place more focus on the diagnosis and treatment of the disease and ignore the influence of parental psychological factors.

As we know, overtreatment is a medical behavior or a medical process, which is caused by a variety of causes exceeding the actual need for diagnosis and treatment of the disease (10). As to the cause of overtreatment, besides the current medical process and ethical aspects, one of the most important contributing factors is the patient expectations or pressure/request, which cannot be ignored during the course of treatment (11,12). At the proliferative phase, IH typically grows rapidly, with the classical clinical manifestations of flushed skin on the face and around the head and neck. This has an enormous effect on the child's appearance, even causing obvious facial deformity (13,14). The physical appearance of the child has a psychological impact on both children and parents (15,16). These complicated psychological states disrupt the clear communication between doctors and patients, thereby undermining the parents or caregiver's understanding of IH and its treatment (17). It is therefore paramount to clearly understand the parents or caregiver's psychological state in order to provide proper counseling for appropriate and effective management (18). Unfortunately, there were previously no standardized questionnaires about the psychological status for Chinese parents with IH children.

To address this, the aim of current study was to design and validate a Psychological Status Questionnaire for Infantile Hemangiomas' parents (IH-PSQ). We hypothesized that IH impacts the affected the parent's emotional and social functioning. This paper describes the development and validation of IH-PSQ instrument for measuring the psychological status of IHs' parents during this early critical period.

We present the following article in accordance with the MDAR reporting checklist (available at https://dx.doi.org/10.21037/tp-21-554).

Methods

The questionnaire was developed according to standard questionnaire development guidelines and methodologies (19) according to the following steps: questionnaire creation, questionnaire validation, and analysis of influencing factors. A multidisciplinary team, composed of health care professionals such as 3 IH experts, 3 psychologists, and 2 IH nursing experts, collaborated with the IH patients and their families.

Statistical analysis

The data collected were entered and analyzed using SPSS 20.0. Statistical analyses included descriptive statistics, factor analyses, reliability analyses, product-moment correlations, independent-sample *t*-tests, One-way ANOVA and regression analyses.

Questionnaire creation

During the conceptual phase, a series interview was conducted with clinicians, patient-reported outcome experts, and IH parents to collect parents' opinions and complaints as the initial interview questions. Semi-structured individual interviews of 10 IH children's parents were then conducted. Participants were asked questions about psychological status for the disease. Answers were transcribed and a content analysis of the responses was carried out according to published methodology, in order to build an initial wording report. Based on this initial wording report, the working group drew up a list of items that were reformulated as simple, comprehensible questions. They evaluated the grammar, wording, and

scaling of each item.

Questionnaire validation

During this phase, the initial questionnaire and the correlated demographic and clinical features questionnaire were administered to a random sample of parents of IH patients (n=350). After reading the informed consent form, the parents completed the questionnaire survey on the spot while waiting at the Clinical Research Center of Vascular Abnormalities in Jiangxi Province, China.

Then, the item analysis of the questionnaire was determined using extreme value comparisons (decision values), entries and total score correlation (including entries and total score correlation, correction entries, and total score), and homogeneity test (including the alpha value after deletion, commonality, and factor load). The validity evaluation of the initial IH-PSQ was mainly based on two aspects: exploratory factor analysis and criterion-related validity. A total of 50 parents of IH children were randomly selected to complete an SAS (Self-rating Anxiety Scale) and SDS (Self-rating Depression Scale) at the same time. Pearson correlation analysis was conducted between the initial IH-PSQ and the scores of SAS and SDS to verify the validity of the questionnaire; The reliability analysis of the initial IH-PSQ was mainly based on three aspects: including internal consistency reliability, split half reliability, and test-retest reliability. Complete data was available for 50 (randomly selected) participants tested at the 2-week interval, to verity the test-retest reliability.

Analysis of influencing factors

In order to exclude the possible interaction between factors, this study used multiple linear regression to analyze the influencing factors of the questionnaire. According to the character of the data, this study set the working conditions of the parents, home address, duration of illness, and the main caregivers as the dummy variables; the educational level of the parents, number of children, monthly income of the family, whether the child had been treated, single or multiple hemangioma, tumor size, and whether there were complications as independent variables, and the score of IH-PSQ as the dependent variable. Backward regression analysis was used to screen the influencing factors of the score of IH-PSQ.

All procedures performed in this study involving human participants were approved by the Ethics Committee of The First Affiliated Hospital of Gannan Medical University (No. LLSC-2021062503) and were in accordance with the Declaration of Helsinki (as revised in 2013). All participants voluntarily participated in the study and signed a written informed consent before taking part.

Results

Questionnaire creation

According to the results of the semi-structured phenomenological interview with the parents of IH children, feelings mentioned more than four times were selected as the initial item (total 35 items), which formed the item pool.

A total of 10 parents of children with IH read the items severally, and proposed amendments on the existence of ambiguity, inaccurate expression, and unrealistic entry. The multidisciplinary team evaluated and corrected the objectivity, accuracy, comprehensiveness, and the form of the questionnaire entries. The initial questionnaire was formed according to the results of this evaluation (*Table 1*). The answer option was based on the LIKERT 5-level system for quantification as follows: "never/not applicable" means 0 point, "rarely" means 1 point, "sometimes" means 2 points, "often" means 3 points, "very often" means 4 points, and "constantly" means 5 points. To prevent confusion with any changes in perception due to symptoms related to comorbidities, the majority of questions included the wording "After your child got IH".

Questionnaire validation

Correlated demographic and clinical features

A total of 350 initial questionnaires were distributed, and the recovery rate was 100%. We excluded 27 questionnaires on account of the questionnaire being incomplete, leaving a total of 323 (92.29%) effective questionnaires.

Table 2 and *Table 3* show the demographic data of the 323 participants and their children, which were collected from their parents through self-reported questionnaires.

Item analysis

The item analysis of the entire initial questionnaire is shown in the *Table 4*, and the criteria for each line are at the bottom of the table. Even if only one rule was violated, the item was deleted. The results showed that item 1, item 4, item 11, item 21, item 26, item 29, item 31, and item 35 did

Table 1 The initial IH-PSQ 35-items (score from 0 to 5)

1. After my child got IH, the time of taking children out to play was less than before
2. After my child got IH, I was depressed and not in a high mood
3. After my child got IH, I was more nervous and anxious than usual
4. After my child got IH, I was worried about the change of condition
5. After my child got IH, I felt God was unfair to me and my child
6.After my child got IH, I felt that my children needed more love than other children
7. After my child got IH, I slept worse than before
8. After my child got IH, my digestion deteriorated
9. After my child got IH, I was afraid to look at the affected part of the child
10. After my child got IH, I would think of my own child and feel uncomfortable when I saw other people's healthy children
11. After my child got IH, I didn't want to talk to others about my child
12. After my child got IH, things were not as interesting as before
13. After my child got IH, I was prone to nightmares
14. After my child got IH, I felt nervous every time we had a doctor's appointment or regular check-up
15. After my child got IH, I attributed the cause of illness to myself
16. After my child got IH, life was not as comfortable as before
17. After my child got IH, I was more likely to be angry than before
18. After my child got IH, I was upset about many things
19. After my child got IH, I worried that our future children would also experience this disease
20. After my child got IH, I felt that this family was not good enough for my child
21. After my child got IH, I felt that others would be biased because of IH
22. After my child got IH, I was more likely to feel tired
23. After my child got IH, I quarreled with the people around me more than before
24. After my child got IH, I was worried that the treatment would affect their growth and development
25. After my child got IH, I felt the IH of other children recovered better than mine
26. After my child got IH, I was afraid to expose the affected areas
27. After my child got IH, I did not want any entertainment
28. After my child got IH, I felt unhappy
29. After my child got IH, I was worried that IH could not be cured
30. After my child got IH, I thought everyone made mistakes
31. After my child got IH, I felt that my child was not as cute as before
32. After my child got IH, my living and working conditions were not as good
33. After my child got IH, it was difficult for me to calm down and think
34. After my child got IH, I sought medical advice everywhere
35. After my child got IH, I felt doctors did not care enough about my child

Tips: with 0= never/not applicable, 1= rarely, 2= sometimes, 3= often, 4= very often, 5= constantly. IH-PSQ: Psychologic Status Questionnaire for parents of Infantile Hemangiomas; IH, infantile hemangioma.

Table 2 Demographic data of the IHs' parents (n=323)

Characteristic	Number	Proportion (%)
Parent		
Father	100	31.0
Mother	223	69.0
Age (years)		
<25	103	31.89
25–40	196	60.68
>40	24	7.43
Home address		
Township or village	208	64.4
County or county city	87	26.9
City or district level city	28	8.7
Number of children		
1	126	39
2	137	42.4
3	21	6.5
>3	39	12.1
Working conditions		
Employed	198	61.3
Unemployed	106	32.8
Requested leave	12	3.7
Retired	7	2.2
Educational level		
Primary school and below	24	7.4
Junior middle school	121	37.5
High school or technical secondary school	123	38.1
College or above	55	17
Family monthly income		
Less than 1,000 yuan	51	15.8
1,000–3,000 yuan	88	27.2
3,000–5,000 yuan	129	39.9
5,000–10,000 yuan	55	17
>10,000 yuan	0	0

IH, infantile hemangioma.

Table 3 General information and disease information of the IHs (n=323)

Characteristic	Number	Proportion (%)
Gender		
Male	89	27.6
Female	234	72.4
Lesion		
Head and neck surface	192	59.4
Trunk	54	16.7
Limbs	60	18.6
Perineum	17	5.3
Duration of illness (months)		
<2	133	41.2
2–4	62	19.2
4–6	48	14.9
>6	80	24.8
Main caregiver		
Parent	80	24.8
Nanny	38	11.8
Grandparent	181	56
Others	24	7.4
Whether to receive treatment		
Treated	215	66.6
Untreated	108	33.3
Single/multiple occurrence		
Single	271	83.9
Multiple	52	16.1
Tumor size (cm^2)		
<1	28	8.7
1–10	208	64.4
>10	87	26.9
Focal depth		
Superficial	250	77.4
Deep type	30	9.3
Mixture	43	13.3
Presence/absence of complications		
Presence	69	21.4
Absence	254	78.6

Table 4 Item analysis of the questionnaire

Item number	Extreme value comparison	Correlation between entry and total score		Homogeneity test			Number of unqualified indicators	Remarks
	Critical ratio	Correlation coefficient	Corrected correlation coefficient	The alpha value of item deletion	Commonality	Factor loading		
1	3.651	0.356	0.310	0.950	0.113	0.336	5	Delete
2	5.124	0.582	0.547	0.948	0.388	0.623	0	Retain
3	13.132	0.644	0.607	0.947	0.389	0.624	0	Retain
4	13.877	0.412	0.362	0.950	0.102	0.320	4	Delete
5	14.946	0.551	0.518	0.948	0.296	0.544	0	Retain
6	17.625	0.649	0.619	0.947	0.411	0.641	0	Retain
7	12.125	0.725	0.696	0.946	0.540	0.735	0	Retain
8	9.184	0.593	0.567	0.948	0.382	0.618	0	Retain
9	9.897	0.681	0.653	0.947	0.423	0.651	0	Retain
10	11.293	0.678	0.647	0.947	0.408	0.639	0	Retain
11	4.968	0.336	0.303	0.949	0.098	0.313	4	Delete
12	7.418	0.550	0.525	0.948	0.339	0.582	0	Retain
13	3.952	0.660	0.638	0.947	0.488	0.698	0	Retain
14	7.528	0.812	0.796	0.946	0.667	0.817	0	Retain
15	14.914	0.803	0.781	0.946	0.618	0.786	0	Retain
16	9.186	0.761	0.741	0.946	0.608	0.780	0	Retain
17	11.656	0.788	0.765	0.946	0.609	0.780	0	Retain
18	6.698	0.694	0.665	0.947	0.495	0.703	0	Retain
19	19.691	0.710	0.685	0.947	0.444	0.666	0	Retain
20	6.461	0.738	0.715	0.946	0.610	0.781	0	Retain
21	4.870	0.203	0.170	0.950	0.021	0.143	5	Delete
22	10.392	0.618	0.587	0.947	0.375	0.613	0	Retain
23	4.706	0.794	0.778	0.946	0.745	0.863	0	Retain
24	25.633	0.760	0.727	0.946	0.496	0.705	0	Retain
25	8.602	0.542	0.508	0.948	0.256	0.506	0	Retain
26	8.999	0.269	0.232	0.950	0.040	0.199	5	Delete
27	4.968	0.808	0.797	0.947	0.766	0.875	0	Retain
28	3.723	0.719	0.703	0.947	0.626	0.791	0	Retain
29	12.341	0.357	0.297	0.951	0.086	0.293	3	Delete
30	5.620	0.808	0.795	0.946	0.751	0.866	0	Retain
31	5.371	0.248	0.225	0.949	0.049	0.221	4	Delete
32	7.336	0.693	0.671	0.947	0.498	0.705	0	Retain
33	7.925	0.716	0.698	0.947	0.587	0.766	0	Retain
34	23.108	0.752	0.731	0.946	0.542	0.736	0	Retain
35	1.946	0.390	0.352	0.949	0.160	0.400	5	Delete
Standard	≥3.000	≥0.400	≥0.400	≤0.949	≥0.200	≥4.500		

not meet the standard, leaving 27 items after their deletion.

Validity evaluation

Factor analysis was used to investigate the construct validity of the questionnaire. The software SPSS 18.0 (IBM Corp., Chicago, IL, USA) showed that Kaiser-Meyer-Olkin (KMO) value was 0.750, and the χ^2 value of Bartlett spherical test was 6,114.620 (P<0.05). There was a significant difference between the correlation coefficient matrix and the unit matrix, indicating that the questionnaire was suitable for factor analysis. The principal component analysis (PCA) method was used to select the orthogonal rotating shaft mode, and the factor with an eigenvalue of greater than 1 was selected.

The results of exploratory factor analysis found that 6 factors could be extracted with a cumulative contribution rate of 85.014%. Factor 6, however, contained only 2 items (item 3 & 12), which did not meet the requirements. Deleted items 3 and 12 could be extracted after 5 factors, with a cumulative contribution rate of 83.239%. All the entries on the corresponding load factor were above 0.4. However, item 13 in the first factor and load on the fifth factor was above 0.4 at the same time, and item 7 in the second factor and the fourth factor load was higher than 0.4 at the same time. By the same method, the second factor analysis, in turn, deleted items 13 and 7. The results showed that the load of all items only on the corresponding factor was above 0.4, which met the requirements of the questionnaire.

According to the contents, the first factor, which included 6 items, demonstrated the degree of depression of parents of children with IH. The second factor, which included 5 items, represented the anxiety level of the parents. The third factor, which included 4 items, represented the psychological balance of the parents. The fourth factor which included 5 items represented the parents' level of fear for the disease. The fifth factor, including 4 items, represented the degree of stigma of the parents due to the disease. These results (*Table 5*) demonstrated a well-structured and more reasonable questionnaire that can better fit parents of children with IH.

Cronbach's α of SAS and SDS were 0.845 and 0.812, respectively, and the correlation coefficients between SAS, SDS, and IH-PSQ were 0.874 and 0.754, respectively (P<0.01), as shown in *Table 6*.

Reliability analysis

Cronbach's α of IH-PSQ was 0.957, while Cronbach's α of 5 factors were 0.941, 0.914, 0.915, 0.849, and 0.839, respectively. The IH-PSQ split-half reliability was 0.971, and the split-half reliabilities of 5 factors were 0.957, 0.879, 0.899, 0.911, and 0.865, respectively (*Table 7*).

The correlation coefficient of test-retest reliability of IH-PSQ was 0.967, and the correlation coefficient of test-retest reliability of 5 factors was 0.987, 0.947, 0.977, 0.967, and 0.947, respectively (*Table 8*).

A final, validated version of IH-PSQ is provided in *Table 9*.

Analysis of influencing factors

According to the survey of the 323 parents of children with IH, the average score of IH-PSQ was 60.20±20.12.

The results of multiple linear regression showed that education level of parents, duration of illness, tumor size, the presence or absence of complications, family monthly income, single or multiple occurrences, and whether to receive treatment entered the regression equation, indicating that these factors will affect the score of IH-PSQ, as shown in *Table 10*.

Discussion

The key reason that catalyzed this study was the unfortunate phenomena of overtreatment among some children with IH. Overtreatment of infants and young children exists in many countries (20). The reasons for this phenomenon included 2 aspects: doctor's reasoning, including the fear of accidents (12), lack of corresponding standards (20), and some moral factors (12); the other was parental psychological factors (11,12). However, it was the guardians who ultimately decided the treatment of IH children. It was of positive significance to explore the psychological state of parents of children with IH in the pursuit of better service of children with IH (18).

The tools of investigation were important in this study. At the beginning, some researchers used the quality-of-life questionnaire to assess IH families (16), and emphasized the necessity for a specific questionnaire (16,18). Next, 2 specialized questionnaires appeared: 1 was the IH-QoL (Infantile Hemangioma Quality-of-Life), which was verified by 220 respondents, containing 29 items, investigating the physical condition and social interaction of children with IH and the emotional and psychological functions of the parents of children with IH (21); The other was the Hemangioma Family Burden (HFB), which was verified by 75 respondents, containing 20 items, investigating family life, relationship and work, emotion/feeling, psychology,

Table 5 Exploratory factor analysis of the questionnaire

Item number	Maximum variation method after direct cross axis factor load					Commonality
	Depression	Anxiety	Psychological balance	Disease fear	Stigma	
22	0.859*	0.029	0.197	0.352	0.181	0.933
2	0.825*	–0.081	0.163	0.165	0.098	0.751
23	0.777*	0.170	0.181	0.325	0.251	0.934
27	0.741*	0.213	0.173	0.381	0.270	0.928
32	0.705*	0.204	0.025	0.025	–0.064	0.813
17	0.586*	0.311	0.144	0.251	0.325	0.883
8	0.200	0.868*	0.114	0.198	0.078	0.852
33	0.332	0.696*	0.140	0.128	0.165	0.908
18	0.036	0.679*	0.192	0.175	0.093	0.874
30	0.211	0.599*	0.170	0.281	0.098	0.848
28	0.053	0.556*	0.165	0.213	0.251	0.718
10	0.341	0.161	0.826*	0.132	–0.060	0.846
5	–0.047	0.067	0.799*	0.344	0.246	0.824
25	0.387	0.291	0.794*	0.094	0.049	0.875
15	0.291	0.378	0.709*	–0.052	0.183	0.934
9	0.132	0.148	0.100	0.806*	0.270	0.772
14	0.304	0.343	0.270	0.700*	–0.042	0.774
19	0.343	0.160	0.130	0.637*	0.153	0.763
34	0.394	0.219	0.355	0.501*	0.277	0.657
24	0.145	0.148	–0.109	–0.040	0.798*	0.847
16	0.165	–0.065	0.381	0.338	0.684*	0.758
6	0.196	0.130	–0.062	0.270	0.651*	0.865
20	0.067	0.018	0.332	0.309	0.599*	0.862
Eigenvalue	6.022	4.113	4.090	3.503	3.081	20.809
Explained variance (%)	24.087	16.453	16.361	14.013	12.325	83.239
Cumulative explanatory variation (%)	24.087	40.540	56.901	70.914	83.239	

*, the numbers are greater than 0.4 and can be included in the entry for the current dimension.

and disease management of the IH family (22). Their research had a positive effect on the better service of IH families. Researchers from another region of China used the IH-QoL to investigate local IH families and got similar results (23). However, we had noticed that the questionnaire mentioned had some regional limitations. We needed to go through a series of processes such as translation and re verification prior to its application. In addition, we required a questionnaire focusing on the psychological status of parents of children with IH, because it has a great impact on the direction of treatment. However, the two above mentioned questionnaires seemed to focus more on the whole IH family. Based on this, we finally decided to develop a regional questionnaire that met our requirements. We would like others to use it in other areas, subject to re-verification.

Table 6 Criterion-related validity of the questionnaire

Characteristic	Score of IH-PSQ	
	Score of the Self-rating Scale	Score of Self-rating Depression Scale
Pearson correlation	0.874	0.754
Significance (bilateral)	<0.01	<0.01
n	50	50

IH-PSQ, Psychologic Status Questionnaire for parents of Infantile Hemangiomas.

Table 7 Internal consistency reliability and split half reliability of the questionnaire

Dimensions of IH-PSQ	Number of items	Cronbach's alpha	Split half reliability
Depression	6	0.941	0.957
Anxiety	5	0.912	0.879
Psychological imbalance	4	0.915	0.899
Disease fear	4	0.849	0.911
Stigma	4	0.839	0.865
The questionnaire	23	0.957	0.971

IH-PSQ, Psychologic Status Questionnaire for parents of Infantile Hemangiomas.

Table 8 Test-retest reliability of each factor and whole questionnaire

Dimensions of IH-PSQ	Number of items	Correlation coefficient
Depression	6	0.987
Anxiety	5	0.947
Psychological balance	4	0.977
Disease fear	4	0.967
Stigma	4	0.947
Whole	23	0.967

IH-PSQ, Psychologic Status Questionnaire for parents of Infantile Hemangiomas.

It was difficult to name this questionnaire. There was no other single questionnaire that involved all the dimensions mentioned in this questionnaire, namely anxiety, depression, psychological imbalance, stigma and fear of the disease, and the survey participants were parents of children with IH. These dimensions actually involved the emotional, psychological, and mental state of parents. After several rounds of team discussions, we finally chose the name of the Psychologic Status Questionnaire for Infantile Hemangiomas' parents (IH-PSQ) because it was more inclusive.

As the location of the survey was the outpatient department of the hospital, the information we gathered was more comprehensive. The possible influencing factors of our questionnaire were more than those of the studies we had previously seen, but it was still not a comprehensive overview. The study showed that there were two aspects affecting the score of the questionnaire: parent-driven factors were monthly income and education level. That means that parents with lower education levels and lower family income are more likely to be affected by psychological conditions such as anxiety and depression; disease-related factors were time of illness, tumor size, presence or absence of complications, single or multiple hemangiomas, and whether they had already been treated. That means the longer the illness, the larger the tumor, the more tumors, complications, and no treatment can make the parents more susceptible to depression, anxiety and other psychological states. Clinicians should focus on those factors in order to better communicate with the parents of children with IH. Some of these factors have been previously mentioned, such as the educational level of parents (23) and the size of the tumor (22,23). Some of the reasons that were not mentioned may be related to the different survey tools and the number of survey-related factors. In addition, what we need to know is that the psychological adjustment ability and positive attitude of parents have a very positive significance to relieve stress and the quality of family life (21). This should be advocated clinically and will help many IH families.

There are two main limitations to the study. The sampling was mainly from the patients of the Clinical Research Center of Vascular Abnormalities in Jiangxi Province, China, which was convenient but had systematic errors. We should enlarge the sample size and include different regions and hospitals so as to reduce the systematic error and selection deviation. Also, our goal of reducing IH overtreatment was only the first step, and we did not identify a link between questionnaire scores and overtreatment. The link will become clearer with the increase of the clinical application of the questionnaire, and we will finally achieve the purpose of reducing overtreatment. What we know is that the parents' psychological distress will be better because of the treatment. When we introduced the treatment of IH to the parents in detail, it was obvious that

Table 9 Final validated version of IH-PSQ

Instructions: here are some questions about your recent psychological status. Please read each question carefully, and then score from 0 to 5 for every item (0= never/not applicable, 1= rarely, 2= sometimes, 3= often, 4= very often, 5= constantly)

1. After my child got IH, I was more likely to feel tired (Depression)
2. After my child got IH, I was worried that the treatment would affect their growth and development (Stigma)
3. After my child got IH, I felt the IH of other children recovered better than mine (Psychological balance)
4. After my child got IH, I would think of my own child and feel uncomfortable when I saw other people's children were healthy (Psychological balance)
5. After my child got IH, I felt that my children needed more love than other children (Stigma)
6. After my child got IH, I worried that the children born to me would also suffer from this disease in the future (Fear)
7. After my child got IH, I was depressed and not in a high mood (Depression)
8. After my child got IH, I was afraid to expose the affected areas (Fear)
9. After my child got IH, I attributed the cause of illness to myself (Psychological balance)
10. After my child got IH, I felt nervous every time the doctor made an appointment or regular check-up (Fear)
11. After my child got IH, I was upset about many things (Anxiety)
12. After my child got IH, I thought everyone made mistakes (Anxiety)
13. After my child got IH, life was not as comfortable as before (Stigma)
14. After my child got IH, It was difficult for me to calm down and think (Anxiety)
15. After my child got IH, my living and working conditions were not good (Depression)
16. After my child got IH, I was prone to nightmares (Depression)
17. After my child got IH, my digestion became worse (Anxiety)
18. After my child got IH, I slept worse than before (Anxiety)
19. After my child got IH, I felt that this family was not good enough for my child (Stigma)
20. After my child got IH, I sought medical advice everywhere (Fear)
21. After my child got IH, I felt God was unfair to me and my child (Psychological balance)
22. After my child got IH, I did not want entertainment (Depression)
23. After my child got IH, I quarreled with the people around me more than before (Depression)

Tips: in practice, it is not necessary to show the brackets after the items. IH-PSQ, Psychologic Status Questionnaire for parents of Infantile Hemangiomas; IH, infantile hemangioma.

Table 10 Multiple linear regression analysis of the influence factors of IH-PSQ

Factors	β value	Standard error	Standard regression coefficient β	t value	P value	Coefficient of determination R^2
Constant term	44.211	3.537		12.500	<0.01	0.348
Education level	10.276	2.659	0.225	3.865	<0.01	
Duration of illness	20.590	3.687	0.372	5.584	<0.01	
Tumor size	−7.038	2.631	−0.146	−2.675	0.008	
Complications	−6.228	2.451	−0.141	−2.540	0.012	
Family monthly income	−5.979	2.405	−0.140	−2.486	0.014	
Single or multiple occurrences	6.128	3.000	0.122	2.043	0.042	
Whether to receive treatment	9.087	4.531	0.111	2.005	0.046	

IH-PSQ, Psychologic Status Questionnaire for parents of Infantile Hemangiomas.

their psychological state was better, which fully indicated that the change of cognition of the disease could help the parents to relieve their psychological distress.

The verification process of the questionnaire involved 323 families with IH. A questionnaire with 5 dimensions was produced through a series of processes such as item analysis, validity analysis, and reliability analysis. The structure and reliability of the questionnaire was supported by strong evidence. The objective assessment of the psychological status of parents of children with IH will enhance communication between the parents and health care providers, thereby improving information transfer, creating a real opportunity for practitioners to gain better understanding of certain issues brought up by the patients or their families, and avoid overtreatment. Moreover, IH-PSQ may help parents of children with IH to understand their psychological status and seek help from psychiatrists to harmonize their daily life.

Conclusions

The IH-PSQ demonstrated its reliability and validity, and can therefore be used to better understand the multidimensional nature of the psychological status of parents of children with IH, including anxiety, depression, psychological imbalance, sense of shame, and disease fear. Using the verified IH-PSQ, we provided further insight into the psychological status of local parents of children with IH and highlighted potential factors for future focus in assisting families with affected children, which include parents' own factors (including monthly income and education level) and disease-related factors (including duration of illness, tumor size, the presence or absence of complications, single or multiple occurrences, and whether treatment should be implemented).

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Footnote

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