The distress and needs of Chinese patients with pituitary adenoma: a preliminary survey

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Abstract

Introduction: It is necessary to investigate the current psychological distress and needs status of patients with pituitary adenoma in China.

Material and methods: Patients with pituitary adenoma treated in our hospital between May 2019 and December 2019 were included. The psychological distress and needs scale for pituitary adenoma patients was used to investigate the psychological distress and needs of patients. Additionally, univariate and multiple linear regression analyses were conducted to analyze the influencing factors.

Results: A total of 254 valid questionnaires were included. The total psychological distress and need score of patients with pituitary adenoma was 23.89 ±18.41 and 21.91 ±20.03 points respectively. There were significant differences in the psychological distress score according to different occupational status, personal income, types of pituitary adenomas, size of pituitary adenoma, invasiveness, endocrine level and history of surgery (all p < 0.05). The size of pituitary adenoma, endocrine level and pituitary adenoma type were the influencing factors of patients' psychological distress (all p < 0.05). There were significant differences in the need score according to different age, occupational status, personal income, types of pituitary adenomas and endocrine level (all p < 0.05). Endocrine level, other rare types of pituitary adenoma and age were the influencing factors of patients' needs (all p < 0.05). Conclusions: Our study is one of the few studies focused on the psychological distress and needs status of Chinese patients with pituitary adenoma. Medical staff should pay attention to the psychological distress of patients with the large, rare type of pituitary adenomas and abnormal endocrine level, and apply appropriate interventions to alleviate their psychological distress.

Key words: distress, needs, pituitary adenoma, China, nursing, care.

Introduction

Pituitary adenoma is a neuroendocrine tumor that originates from the anterior pituitary. It is the most common pituitary disease, accounting for about 10–15% of intracranial tumors [1]. Pituitary adenomas cause mass effect and endocrine disorders [2, 3]. The space-occupying effect causes neurological symptoms such as headache, dizziness, decreased vision,

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and visual field defects [4]. Growth hormone adenoma causes excessive growth of soft tissues and bones in the patient's body, and excessive growth hormone also affects multiple systems and organs in the patient's body [5]. Even after active surgery, and drug and radiotherapy treatment, not all patients' symptoms can be improved. Faced with problems such as unimprovable symptoms, long-term effects of hormone overdose, the possibility of tumor recurrence, long-term medication and hormone monitoring, patients can also suffer from certain psychological distress, which affects their quality of life [6]. In addition, in the course of long-term illness, patients still have a series of needs, which affect their effective response to the disease [7]. An in-depth understanding of the psychological distress and needs of patients with pituitary adenoma is of great significance for improving the quality of life of patients.

Many studies [8, 9] have shown that patients with pituitary adenoma have certain psychological distress and it seriously affects their quality of life. Studies [10, 11] have shown that compared with healthy controls, patients with pituitary diseases have a higher prevalence of severe depression and adjustment disorders, and patients with pituitary diseases have a higher incidence of psychosomatic syndromes such as irritability, low morale, and continuous somatization. Moreover, patients with pituitary adenoma have different needs. A qualitative study [12] reported that patients hope to obtain more information about diseases from medical staff, such as adverse drug reactions, the effects of diseases on physical, mental, cognitive, sexual function and fertility. Patients expect medical staff to give more advice on stress management and lifestyle [13]. Understanding the current psychological distress and needs of patients with pituitary adenoma can provide a scientific basis for formulating targeted intervention measures. However, there are few studies on the psychological distress and needs of patients with pituitary adenomas, which needs further investigations. Therefore, this study aimed to understand the psychological distress and needs of patients with pituitary adenoma in China, and analyze the influencing factors of psychological distress and needs of patients with pituitary adenoma, to provide a theoretical basis for the management of pituitarv adenoma.

Material and methods

Ethical consideration

In this study, all methods were conducted in accordance with the relevant guidelines and regulations. This study passed the ethical review of our hospital (review number: ECSU-20019000115), and all included patients agreed to participate in this study, and written informed consents had been obtained from all the included patients.

Sample size calculation

It has been reported [14] that factor analysis should be conducted for generally less than 40 items. In most cases, a sample size of 200 is sufficient. It was considered [15] that for factor analysis, the number of pre-samples should be 5 times the number of entries; if the ratio of the number of pre-samples to the number of entries was 10 : 1, the result would be more stable. The number of items in our survey scale is 33. Except for one open question, it was estimated that there were 32 items for factor analysis. According to the principle of sample size calculation, the sample size should be 160 to 320.

Patients

We adopted the convenience sampling method and selected patients with pituitary adenoma who had been treated in the Department of Neurosurgery of our hospital from May 2019 to December 2019 as the research populations. The inclusion criteria for patients in this study were as follows: 1) age \geq 18 years old; 2) patients were diagnosed with pituitary adenoma; 3) patients voluntarily participated in this study; 4) patients received pituitary adenoma surgery or related medical treatment for 3 months or more.

The exclusion criteria of patients in this study were as follows: 1) those patients who could not communicate normally and finished the survey; 2) patients with previous mental illnesses such as schizophrenia and depression or dementia; 3) patients who did not agree to participant in this study.

Survey tools

General information

The demographic information included age, gender, education level, and medical insurance type. The disease-related information included pituitary adenoma classification, pituitary adenoma size, invasiveness, surgical status and medication. Tumor invasiveness was defined according to the Knosp invasiveness grade of pituitary adenoma: Knosp grade \geq 3 indicated that the tumor was aggressive; Knosp grade \leq 2 indicated that the tumor was not invasive.

Psychological distress and needs scale

The psychological distress and needs in patients with pituitary adenoma were investigated by the Chinese version of the psychological distress and needs scale for patients with pituitary adenoma [16]. The item level content validity index (I-CVI) of each item in the Chinese version of the scale was 0.833-1, and the average scale level content validity index (S-CVI) was 0.958. The Cronbach's α coefficient in the "mental distress" part was 0.945, and the test-retest reliability was 0.917; the Cronbach's α in the "needs" part was 0.950, and the test-retest reliability was 0.913. The scale contained a total of 28 items. The first 27 items evaluated five dimensions: emotional problems, social function, physical and cognitive problems, negative disease perception, and sexual function. The scale adopted a percentile scoring method. The scores of each dimension and the total scale were 0-100 points. The calculation formula was: dimension (total scale) score = actual score of the dimension (total scale)/highest possible score × 100. The higher the psychological distress score was, the more serious was the psychological distress, the higher was the demand score, and the more the patient expected support from medical staff.

Data collection and quality control

We selected appropriate pituitary adenoma patients based on the inclusion and exclusion criteria established by the study, and the investigator himself explained the purpose and significance of the study to the patient, and issued informed consent and questionnaires. In the case of informed consent, a unified guideline was used to introduce the method and requirements for filling out the questionnaire in this study, which was filled out by the patient himself. If patients had any questions during the questionnaire filling process, we used unified explanatory language to answer patients. After completing the questionnaire, the researchers conducted on-site quality control, including checked the guestionnaire item by item to check the incomplete or unclear information with obvious logical errors.

Ethics approval and consent to participate

In this study, all methods were performed in accordance with the relevant guidelines and regulations. This study passed the ethical review of our hospital (review number: ECSU-20019000115), and all included patients had agreed to participate in this study, and written informed consents had been obtained from all the included patients.

Statistical analysis

We used SPSS25.0 for statistical analysis of the data. The measurement data were expressed as mean \pm standard deviation, and the counting data were expressed as frequency and percentage. The *t*-test and analysis of variance were used for sin-

gle factor analysis with the Bonferroni method, and multiple linear regression was used to analyze the influence of various factors on the psychological distress and needs of patients with pituitary adenoma. In this study, the difference was statistically significant when p < 0.05.

Results

Characteristics of included patients

A total of 270 questionnaires were distributed, and 254 valid questionnaires were returned. The effective response rate was 94.07%. As presented in Table I, the patients were 20–72 years old, with an average age of 41.32 \pm 12.45 years. Among them, 15 (5.90%) patients received gamma knife treatment, 178 (70.1%) patients received surgery, 12 (6.74%) patients only received transnasal sphenoid approach surgery, 5 (2.81%) patients received both craniotomy and transnasal sphenoid approach surgery, and 28 (11.02%) patients took anti-depressant treatment after surgery. The characteristics of included patients are presented in Table I.

Psychological distress and needs in patients with pituitary adenoma

The total psychological distress score of patients with pituitary adenoma was 23.89 ± 18.41 points, of which the negative disease perception dimension score was the highest, and the social function dimension score was the lowest. The total need score of patients with pituitary adenoma was 21.91 ± 20.03 points, of which the negative disease perception dimension scored the highest, and the social function dimension scored the lowest number of points (Table II).

As presented in Table III, univariate analysis indicated that there were significant differences of psychological distress score according to different occupational status, personal income, types of pituitary adenomas, size of pituitary adenoma, invasiveness, endocrine level and history of surgery (all p < 0.05).

As presented in Table IV, multiple linear regression analysis showed that the size of pituitary adenoma, endocrine level and pituitary adenoma type were the influencing factors of patients' psychological distress (all p < 0.05).

As presented in Table V, univariate analysis indicated that there were significant differences of need score according to different age, occupational status, personal income, types of pituitary adenomas and endocrine level (all p < 0.05).

As presented in Table VI, multiple linear regression analysis showed that endocrine level, other rare types of pituitary adenoma and age were the influencing factors of patients' needs (all p < 0.05).

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Items	Cases (%)	Items
Age:		Medical insurance:
≤ 44	164 (64.2)	Self-covered
45–59	62 (24.4)	New rural cooperative medi
 ≥ 60	28 (11.0)	insurance
Gender:		Medical insurance for urbar residents
Female	173 (68.1)	Types of pituitary adenomas:
Male	81 (31.9)	Growth hormone type
Marital status:		Corticotropin type
Married	217 (85.4)	Non-function type
Unmarried	34 (13.4)	Prolactin type
Divorced	3 (1.2)	Other rare types
Child bearing:		Size of pituitary adenoma:
Yes	205 (80.7)	Microadenoma
No	49 (19.3)	Large adenoma
Occupational status:		Giant adenoma
Employed	209 (82.3)	Invasiveness:
Unemployed/retired	45 (17.7)	Yes
Education level:		No
Primary school	26 (10.2)	Endocrine level:
Junior high school	53 (20.9)	Normal
High school or occupational technique school	50 (19.7)	Abnormal
University	125 (49.2)	History of surgery:
Personal income (RMB):		Yes
None	26 (10.2)	No
< 3000	56 (22.0)	Anti-depressants use after sur
3000–6000	93 (36.6)	Yes
> 6000	79 (31.1)	No

 Table I. Characteristics of included patients (n = 254)

 Table II. Psychological distress and need scores of patients with pituitary adenoma

Dimensions	Psychological distress score	Needs scores
Emotional problems	26.92 ±23.28	25.49 ±26.62
Social function	11.71 ±18.05	10.65 ±18.27
Physical and cognitive problems	27.39 ±21.54	27.61 ±24.54
Negative disease perception	34.82 ±23.95	35.41 ±27.42
Sexual function	14.22 ±23.73	15.16 ±27.38
Total scale score	23.89 ±18.41	21.91 ±20.03

Discussion

A total of 254 patients with pituitary adenoma were investigated in this study. Among them, prolactin type patients were the most numerous, followed by non-functioning patients, acromegaly patients, Cushing's disease patients, and other rare type patients. Our findings are similar to previous related epidemiological survey results [17, 18], in which the prevalence of prolactinoma is the highest, followed by non-functioning type, acromegaly and Cushing's disease. Although the prevalence of acromegaly and Cushing's disease is relatively low, China's population base is large and the number of patients is also large [19]. The psychological distress and needs scale of patients with pituitary adenoma is a self-rating scale, which requires higher reading comprehension of patients [20]. Also,

Cases (%)

25 (9.8)

33 (13.0)

196 (77.2)

55 (21.7) 20 (7.9) 76 (29.9) 93 (36.6) 10 (3.9)

88 (34.6) 155 (61.0) 11 (4.3)

65 (25.6) 189 (74.4)

111 (43.7) 143 (56.3)

178 (70.1) 76 (29.9)

28 (11.02) 226 (88.98)

Variables	Psychological distress scores	F/t	P-value
Age:			
< 60	24.81 ±20.24	0.389	0.698
≥ 60	23.84 ±15.24		
Gender:			
Female	22.53 ±17.69	-1.727	0.085
Male	26.79 ±19.64		
Marital status;			
Married	24.24 ±18.69	0.295	0.745
Unmarried	22.11 ±16.91		
Divorced	19.14 ±18.06		
Child bearing:			
Yes	24.07 ±18.95	0.322	0.748
No	23.12 ±16.10		
Occupational status:			
Employed	22.68 ±16.40	-2.274	0.024
Unemployed/retired	29.51±25.25		
Education level:			
Primary school	30.06 ±15.99	1.529	0.208
Junior high school	20.74 ±15.80	/	0.200
High school or occupational technique school	23.30 ±19.62		
University	24.19 ±19.25		
Personal income (RMB):	21.17 ±17.25		
None	36.18 ±28.49	4.892	0.003
< 3000	20.35 ±15.05	4.072	0.005
3000-6000	23.63 ±15.83		
> 6000	23.65 ±13.85		
Medical insurance:	22.07 ±17.90		
Self-covered	26 74 112 00	0.404	0.668
	26.74 ±18.90	0.404	0.008
New rural cooperative medical insurance Medical insurance for urban residents	24.72 ±19.51		
	23.39 ±18.22		
Types of pituitary adenomas:	27.72.10.27	2.072	0.004
Growth hormone type	27.72 ±19.37	3.973	0.004
Corticotropin type	29.26 ±21.09		
Non-function type	22.36 ±16.63		
Prolactin type	20.11 ±17.77		
Other rare types	38.89 ±15.15		
Size of pituitary adenoma:			
Microadenoma	20.74 ±19.56	3.690	0.026
Large adenoma	24.87 ±17.30		
Giant adenoma	35.27 ±19.69		
Invasiveness:			
Yes	28.39 ±19.40	2.303	0.022
No	22.34 ±17.85		
Endocrine level:			
Normal	18.15 ±14.45	-4.727	< 0.001
Abnormal	28.35 ±19.90		
History of surgery:			
Yes	26.00 ±19.16	2.830	0.005
No	18.96 ±15.54		

Table III. Univariate analysis of psychological distress scores in patients with pituitary adenoma

 Table IV. Multiple linear regression analysis of influencing factors of psychological distress in patients with pituitary adenoma

Variables	β	SE	t	P-value
Constant	7.574	5.886	1.287	0.199
Size of pituitary adenoma	5.800	2.532	2.291	0.023
Endocrine level	10.162	2.460	4.130	0.000
Corticotropin type of pituitary adenomas	5.653	4.701	1.203	0.230
Non-function type of pituitary adenoma	0.202	3.420	0.059	0.953
Prolactin type of pituitary adenoma	-0.801	3.453	-0.232	0.817
Other rare types of pituitary adenoma	13.761	5.977	2.302	0.022

patients with a higher education level pay more attention to their own psychosocial problems, and they will have better acceptance of the survey and a higher degree of cooperation [21, 22].

The results of this study showed that unemployed patients have higher psychological distress and need scores than working patients, and non-income patients have higher psychological distress and demand levels. A previous study [23] found that occupation is one of the influencing factors of the quality of life of patients with pituitary adenoma. It has been reported [24, 25] that 28% of patients with pituitary adenoma have no paid work, and Cushing's disease has the highest proportion of unpaid work, reaching 47%. Working patients can be distracted to a certain extent through work [26]. Not only can they get financial support from the job, but they can also get more information and social support to promote the patient's physical and mental health [27, 28]. Therefore, medical staff should pay more attention to the psychological state and needs of patients with pituitary adenoma who are not working and have no stable income, and help patients choose cost-effective treatment options to reduce the psychological burden of medical expenses on patients [29].

We found that patients with other rare types of pituitary adenomas have the highest levels of psychological distress and needs. The possible reason may be that the mixed adenomas can secrete multiple hormones, leading to a variety of endocrine disorders [30]. The clinical manifestations are diverse, overlapping, and more complex, which causes a greater psychological burden on patients and more needs. Patients with thyroid stimulating hormone adenoma and gonadotropin adenoma often seek medical treatment in multiple departments, and the medical treatment process is often complicated and tortuous [31]. Therefore, medical staff should pay special attention to the psychological conditions of patients with rare type pituitary adenomas, explain the clinical manifestations, treatment plans, and post-treatment of the disease, help patients build confidence in treating the disease, and alleviate the psychological distress of patients. Additionally, it is necessary to understand the needs of patients and develop a personalized care plan.

Endocrine level is an important factor affecting patients' psychological distress and needs. Studies [31, 32] have shown that after active treatments such as surgery and radiotherapy, residual functional pituitary adenomas will secrete excessive hormones. At present, relevant research focuses on the health management of patients with pituitary adenomas during the perioperative period, while neglecting the long-term follow-up health management of patients with pituitary adenomas that have developed into chronic diseases [33]. Therefore, patients with pituitary adenomas in long-term follow-up urgently need effective health management to improve their self-management ability, reduce their psychological burden and improve their quality of life.

The larger the pituitary adenoma, the more aggressive it is, and the higher the level of psychological distress in patients with a history of surgery. A previous study [34] showed that the size of preoperative pituitary adenomas is a factor that affects the total resection rate of endoscopic sinus surgery. The larger the preoperative pituitary adenoma size, the lower is the total resection rate [35]. In large adenomas and giant adenomas, the total cut rate under the microscope is 14.3–56.4% [36]. Patients with incomplete pituitary adenomas have a low endocrine remission rate [37]. Furthermore, patients undergoing surgery will undergo longer-term recovery, and complications such as hypopituitarism and diabetes insipidus may occur after surgery [38-40]. Therefore, medical staff should pay attention to the psychological distress and needs of patients with giant adenomas, surgical history, and invasive pituitary adenomas.

This present study revealed that patients under the age of 60 have a higher level of needs than those over the age of 60. The possible reason may be that young patients with pituitary adenomas need to return to work, and their social and family responsibilities are heavier [41, 42]. Also, Table V. Univariate analysis of needs in patients with pituitary adenoma

Variables	Need scores	F/t	P-value
Age:			
< 60	22.63 ±20.54	2.161	0.036
≥ 60	16.10 ±14.24		
Gender:			
Female	20.46 ±19.29	-1.700	0.090
Male	25.02 ±21.33		
Marital status:			
Married	22.02 ±20.24	0.085	0.918
Unmarried	21.65 ±19.23		
Divorced	17.28 ±19.21		
Child bearing:			
Yes	21.95 ±20.58	0.056	0.956
No	21.77 ±17.75		
Occupational status:			
Employed	20.68 ±18.25	-2.119	0.035
Unemployed/retired	27.61 ±26.33		
Education level:			
Primary school	27.74 ±16.39	1.815	0.145
Junior high school	17.26 ±17.62		
High school or occupational technique school	21.37 ±20.72		
University	22.89 ±21.15		
Personal income (RMB):			
None	34.87 ±28.56	5.274	0.002
< 3000	16.53 ±16.19		
3000–6000	22.22 ±18.53		
> 6000	21.10 ±19.30		
Medical insurance:			
Self-covered	25.85 ±20.39	0.540	0.583
New rural cooperative medical insurance	21.54 ±20.06		
Medical insurance for urban residents	21.13 ±19.85		
Types of pituitary adenomas:			
Growth hormone type	24.75 ±21.20	2.644	0.034
Corticotropin type	26.16 ±23.12		
Non-function type	19.37 ±17.79	·	
Prolactin type	19.73 ±20.11		
Other rare types	37.41±15.00		
Size of pituitary adenoma:	5711215100		
Microadenoma	19.54 ±21.00	2.242	0.108
Large adenoma	22.51 ±19.09		5.105
Giant adenoma	32.49 ±22.91		
Invasiveness:			
Yes	25.68 ±21.27	1.767	0.078
No	20.62 ±19.48	1.707	0.070
Endocrine level:	20.02 117.40		
Normal	16.07 ±16.49	-4.226	< 0.001
Abnormal	26.44 ±21.38	-4.220	10.001
History of surgery:	20.44 121.30		
	72 20 ±20 07	1 700	0 073
Yes	23.38 ±20.87	1.798	0.073
No	18.47 ±17.58		

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Variables	β	SE	t	<i>P</i> -value
Constant	24.872	4.797	5.185	0.000
Endocrine level	9.489	2.726	3.481	0.001
Corticotropin type of pituitary adenomas	2.242	5.018	0.447	0.655
Non-function type of pituitary adenoma	1.569	3.849	0.408	0.684
Prolactin type of pituitary adenoma	-1.656	3.385	-0.489	0.625
Other rare types of pituitary adenoma	15.642	6.618	2.364	0.019
Personal income (RMB)	-1.119	1.531	-0.731	0.465
Age	-9.394	4.295	-2.187	0.030
Occupation	-7.063	3.946	-1.790	0.075

Table VI. Multiple linear regression analysis of influencing factors of needs in patients with pituitary adenomas

pituitary adenomas may cause changes in the patient's appearance, affecting marriage, childbirth, and sexual life [43]. Young patients pay more attention to the long-term adverse effects of the disease and have higher expectations for recovery [44]. Therefore, it is necessary to strengthen the long-term follow-up of young patients, teach patients to manage their own health and provide certain psychological support to meet the needs of patients.

There are several shortcomings in this study that must be considered. Firstly, the influencing factors included in this study explain only 13.7% and 12.4% of the psychological distress and needs variation of patients with pituitary adenoma. Other factors such as drug treatment, duration of illness, and disease acceptance were not considered. It is recommended that future studies expand the scope of influencing factors and explore other factors that may be involved in the psychological distress and needs of patients with pituitary adenomas. Secondly, the research subjects included in this study were patients who had undergone surgery or medication for 3 months or more, and the results of the study are applicable to patients who have been followed up out of hospital for a long time. It is suggested that follow-up studies can also include hospitalized patients and patients in the recovery stage within 3 months after surgery to explore the psychological distress and needs of patients with pituitary adenomas at different stages of the disease. Thirdly, due to the limitations of manpower and material resources and the low incidence of some types of pituitary adenomas, there are only 20 patients with Cushing's disease in the investigation, which cannot well represent the psychological distress and level of needs of patients with Cushing's disease. Our study is one of the few studies focused on the psychological distress and needs status of Chinese patients with pituitary adenoma. We will continue to include patients with Cushing's disease, expand the sample size, and analyze the psychological distress and needs of patients with Cushing's disease more comprehensively in the future.

In conclusion, patients with pituitary adenomas have certain psychological distress and needs, especially in the dimensions of perception of negative diseases, physical and cognitive problems. Patients who are unemployed or retired, with lower income, rarely typed pituitary adenomas and abnormal endocrine levels have higher levels of psychological distress and needs. Clinically, attention should be paid to the above-mentioned patients' psychological distress and needs, and targeted support and psychological interventions should be given to improve patients' self-management ability and quality of life.

Conflict of interest

The authors declare no conflict of interest.

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