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Qualitative descriptive study during the COVID-19 pandemic on the needs of informal caregivers of Chinese minors who underwent craniopharyngioma surgery

Kun Du ^a, Yuan Yuan Pan ^{b,*}, Wen Wen Yan ^b

^a Emergency Center, The First Affiliated Hospital of Zhengzhou University, Zhengzhou, China

^b Department of Neurosurgery, The First Affiliated Hospital of Zhengzhou University, Zhengzhou, China

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ABSTRACT

Purpose: To determine the needs of informal caregivers during the long-term health management of minors who have undergone craniopharyngioma surgery.

Design and methodology

This is a qualitative and descriptive research study. Purposive sampling was used to select participants, and semi-structured interviews were conducted to explore the needs of 21 informal caregivers for postoperative minors. Due to the COVID-19 pandemic, the respondents were provided with the options of online video call or offline one-on-one interviews. Following this, a content analysis method was conducted.

Results: Four themes and 14 sub-themes were extracted from the results of the study, including needs for relieving psychological stress (including psychological pressure on both minors and on caregivers); requirement for on-campus assistance (physical activity, eliminating verbal violence in schools, special education needs for child, healthcare services provided by school hospitals); demands for medical help (acquiring medical knowledge, need for medication management, convenience and reliable access to medical services, need for technological development, expectations of multidisciplinary cooperation, the necessity of health review reminders); and the desire for financial aid (charity platform assistance, inclination of government policy).

Conclusions: In China, informal caregivers of young patients with onset craniopharyngioma require both the multidisciplinary cooperation of medical institutions and the multi-departmental cooperation of society. Information and medical technology advancements may benefit families with young patients. Improving community hospitals' medical services and encouraging the practical use of online medical treatment and prescriptions are both necessary in the context of COVID-19.

Practice implications: By identifying the needs of informal caregivers, medical professionals are able to develop care plans and interventions aimed at reducing the burden of care for minors who have undergone craniopharyngioma surgery.

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Craniopharyngioma is a benign intracranial tumor originating from residual epithelial cells of the embryonic Rathke's pouch that extends along the craniopharyngeal duct (Müller, 2020; Müller et al., 2019). According to Müller et al. (2019), the onset of craniopharyngioma in children occurs most frequently between the ages of 5 and 15. Globally, the incidence of craniopharyngioma is 0.5–2.5 new cases for every one million people a year (Zacharia et al., 2012). There was no significant difference in incidence between male and females, and racially, the

rate was highest in Blacks, followed by Whites, Asian or Pacific Islanders, and American Indian/Alaska Natives (Momin et al., 2021).

The tumor is adjacent to the optic nerve, pituitary, hypothalamus, internal carotid artery system and other crucial locations (Louis et al., 2016). Consequently, children who undergo craniopharyngioma surgery have a very high survival rate—the 10-year survival rate is over 90%. However, no child is immune to long-term complications, such as visual impairment, hypothalamic dysfunction, neurological dysfunction, cerebrovascular disease, and endocrinopathy (Drapeau et al., 2019; Steinbok, 2015). The surgical procedure and tumor site are highly correlated with the recurrence rate of craniopharyngioma (Park et al., 2020). Children who received growth hormone replacement therapy had a post-operative rate of 10.9%, compared to 35.2% of children who did

* Corresponding author at: The First Affiliated Hospital of Zhengzhou University, No. 1 East Jianshe Road, Erqi District, Zhengzhou City, Henan Province 450000, China.
E-mail address: tuantuan0723@126.com (Y.Y. Pan).

not (Alotaibi et al., 2018). The long-term recurrence rate of craniopharyngioma is 18%, and its mortality rate is 3 to 4 times that of the general population (Pereira et al., 2005). Furthermore, evidence suggests that craniopharyngioma impacts young patients more than adult patients. Adults who experienced childhood craniopharyngioma had difficulties adjusting to their new lives on a psychosocial level and integrating into the workplace as adults (Memmesheimer et al., 2017; Sterkenburg et al., 2015). These difficulties were primarily exhibited by decreased physical function, physical exhaustion, infertility, elevated depression levels, and other symptoms (Memmesheimer et al., 2017; Sterkenburg et al., 2015). In summary, patients who have undergone craniopharyngioma surgery encounter numerous complications, long-term damage, a high rate of recurrence and mortality, and poor future psychological adaptation.

Surgery itself does not relieve the psychological burden on informal caregivers of children with cerebral diseases (Leal et al., 2020). Following craniopharyngioma surgery, the lives of family members are significantly affected; they may find themselves extremely concerned about their children's health (Laffond et al., 2012). Childhood cerebral tumor survivors' caregivers, particularly females, reported lower perceptions of social support and greater caregiver burden (Bates et al., 2022). Depression is a common psychological issue among caregivers of young brain tumor patients (Choi et al., 2016). Caregivers and the environment they provide have a significant impact on how well children recover after brain tumor surgery. Depressed parents exhibit less empathy, responsiveness, and more hostility towards their child with a brain tumor (Choi et al., 2016). Interaction between caregivers and patients is essential (Serçe & Günüşen, 2021). There is evidence to suggest that informal caregiver stress affects psychosocial outcomes of children (Lim et al., 2019). In addition, a harmonious family environment and appropriate guidance provided by an informal caregiver are successful in treating hypothalamic obesity following surgery for a craniopharyngioma (Meijneke et al., 2015). For these reasons, exploring the causes of informal caregivers' burden has received considerable scholarly attention.

Many studies have discussed informal caregivers' difficulties in the care burden for a variety of diseases (Thana et al., 2021). Indeed, informal caregivers experience depression, stress, and physical illnesses, which may be a result of unmet needs (McCabe et al., 2016; Sklenarova et al., 2015). Exploring the needs of informal caregivers can provide guidance for the setting of responsive and adaptable support programs, which are fundamental for professionals to provide high-quality nursing (Harding & Higginson, 2003; Paterson et al., 2018). Therefore, our study aims to investigate the needs of informal caregivers of children with craniopharyngioma following cerebral surgery. To our knowledge, this study is the first to have been conducted on informal caregiving following craniopharyngioma surgery in China.

Method

Research design

To identify and comprehend the needs of informal caregivers under the long-term care process for Chinese minors who have undergone craniopharyngioma surgery, a qualitative descriptive study was conducted. The most representative respondents were chosen through purposive sampling after careful consideration of all caregiver-related, patient-related, and family-related factors. In terms of the caregiver-related factors, the sampling criteria included gender, age, employment status, education level, and the length of care provided. In terms of patient-related factors, we considered the patients' gender, age at the time of surgery, length of procedure, tumor recurrence, and level of education. We considered the relationship and monthly family income when determining family-related factors.

At the end of a routine follow-up telephone consultation, an interview invitation was extended to the informal caregiver. After obtaining

oral consent, we sent the informed consent form via their social platform account, and conducted online or offline interviews as per their preference during the COVID-19 pandemic. In the online interviews, the interviewer video called with the interviewee in a private, quiet office or break room, during which the interviewee was asked to ensure there was no interference. In the offline interviews, the interviewer spoke with the interviewee one-on-one in a quiet lounge. All interviewees received gifts at the end of the session, as well as financial aid to cover their travel and lodging costs in accordance with their individual circumstances.

The following criteria were used to determine which caregivers were included in the study: a caregiver of a minor who has undergone craniopharyngioma surgery; an informal caregiver (according to Chiao et al. (2015), this is someone who offers unpaid assistance to another independent person who has medical, psychological, or developmental needs for social or familial interaction); a caregiver who voluntarily participated in this study and signed informed consent. The exclusion criteria for children and caregivers were insufficient Chinese language skills, and cognitive impairment.

To create an initial draft of the outline interview, a literature review and group discussions were conducted. Based on the outline, two pilot tests were conducted. After the two interviews, we changed the questions that were not conducive in an oral setting. Appendix A contains the final interview guide. Interviews were conducted from January to April 2022.

The research team for this study invited one national second-level psychological consultant, who conducted identical interview training for team members before the qualitative study began. The two trained researchers who have in-depth knowledge of craniopharyngioma post-operative nursing were chosen as the interviewers for this study. The fact that the two interviewers were the nurses in charge of these patients during their hospitalization is important to note, because it made building trust with the families much simpler. All interviews were recorded with the participants' permission. On an average, 28 to 56 min were allotted for each interview. The "data saturation" principle was accepted as the standard to determine sample size within the qualitative designs, which can be applied to the point where no new information emerges from the study participants during data collection (Bradshaw et al., 2017). This study adhered strictly to this rule, so data saturation was accomplished. 21 caregivers in total were interviewed, and Table 1 summarizes their characteristics.

Data analysis

A standard content analysis was employed to analyze the interview text, with an inductive data driven process coding and theme development (Fereday & Muir-Cochrane, 2006; Moser & Korstjens, 2018). First, each document was thoroughly examined by two researchers, and we repeatedly listened to the audio to fully understand the data. We then coded and analyzed transcribed documents and interview notes manually and independently. Next, we compared the extracted coding information and the primary themes respectively, and reached a consensus after discussion with other members. Then, while simultaneously gathering and analyzing data, we gradually created themes and sub-themes. All the statements were reviewed in order to compile them for reporting.

Ethics

The research program was approved by the Scientific Research Office in the First Affiliated Hospital of ** University (No. KY-2022-0124). All respondents were fully informed by the researchers about the purpose and content of the study, and all respondents signed their informed consent. Before the start of the interviews, the researchers assured the respondents that their real names would not be used in any of the recordings; they would rather be named as numbers in accordance

Table 1
Description of demographic data.

Categories	Values
Informal caregivers	
Age(years), mean(SD)	42.5(9.8)
Gender	
Female	12(57.1%)
Male	9(42.9%)
Location	
Rural	11(52.4%)
Urban	10(47.6%)
Education	
Master degree or above	1(4.8%)
College or Bachelor Degree	3(14.3%)
High School or Below	17(80.9%)
Full-time	
Yes	10(47.6%)
No	11(52.4%)
Length of care (Years)	
≤3Y	19(90.5%)
>3Y	2(9.5%)
Patients	
Gender	
Boy	11(52.4%)
Girl	10(47.6%)
In education	
Yes	12(57.1%)
No	9(42.9%)
Age (years), means (SD)	12.1(3.6)
Relapse	
Yes	4(19.0%)
No	16(76.2%)
Unknown	1(4.8%)
Families	
Relationships between caregivers and patients	
Parents-child	20(95.2%)
Grandparents-child	1(4.8%)
Monthly Household Income(Yuan)	
≤10,000	16(76.2%)
>10,000	5(23.8%)

with the order of the interviews. The researchers also explained to the respondents the need for recording the interviews; and promised that all recordings would be destroyed as soon as the publication is accepted, and the transcripts would be kept in a safe and secured manner. The researchers also provided written confirmation that all personal information would remain anonymous when reporting publicly on this study.

Rigor

To ensure the reliability of qualitative description research, the principle created and introduced by Lincoln and Guba in the 1980s was employed in the study (Lincoln & Guba, 1986). Firstly, the researchers tried to interview caregivers of patients who underwent surgery in our hospital, particularly in our department. The prior rapport was helpful for fostering a trustworthy relationship throughout the prolonged hospitalization. Secondly, during the interview, questions were not asked in a predetermined order, and we also respected the interviewees' wish to talk and turned the topic back only if they deviated markedly from the interview theme. In addition to the audio, the researcher also noted interviewees' expressions, body movements, intonation and other non-verbal behaviors during the process. Thirdly, interviewers kept reflective journals which were very useful because they allowed them to fully immerse themselves in the research. Each document was reviewed by two researchers, one being the text interviewer and the other being the first author of this article. Finally, in order to validate the findings, we returned to the caregivers of the children who had taken part in the study. Direct quotes from participants were then used to support the findings.

Results

Only four people participated in face-to-face interviews with researchers, and 17 chose online video interviews instead owing to the COVID-19 outbreak. Table 2 provides a summary of the respondents' percentage distribution. As shown in Table 3, we found 4 themes, 14 sub-themes, and 38 codes. These needs of informal caregivers included: needs for relieving psychological stress, requirement for on-campus assistance, demands for medical help, and the desire for financial aid. Below is a description of these requirements in more detail.

Needs for relieving psychological stress

According to the majority of informal caregivers (15/21) who reported psychological stress, both caregivers and young patients needed psychological support. (#01, #02, #03, #04, #05, #09, #12, #13, #15, #16, #17, #18, #19, #20, #21).

Relieving the psychological pressure of caregivers

During the first year of surgery, the informal caregivers (#01, #02, #03, #05, #15, #16, #18) were primarily troubled by complications, especially the presence of symptoms associated with craniopharyngioma, such as headache, blurred vision, abnormal urine, high body temperature, and so on. Any discomfort expressed by the child has the potential to increase their level of mental stress. It was not an overstatement to say that everything the doctor said to them both before and after the procedure stuck in their minds. The location of craniopharyngioma, the difficulty of surgery, and the unpredictability of the child's future health made them feel utterly out of control. So, after the initial period post-surgery, the main psychological concerns of informal caregivers (#04, #05, #12, #13, #20) were the recurrence of craniopharyngioma and the fear of returning to work. Caregivers (#01, #02, #03, #04, #09, #16) were so preoccupied with the health of their patients that they almost forgot about their own responsibilities. They were afraid to shift their focus in life when they should have gone back to work. Almost half of the caregivers were full-time caregivers who were permanently immersed in their children's illness and pain. In addition to height and weight, when postoperative patients reached puberty, the development of secondary sexual characteristics and fertility came to the attention of caregivers (#12, #16, #20, #21). Traditionally, it has been assumed that brain surgery has an impact on a person's intelligence. Only a few informal caregivers (#15) described how uncomfortable they felt about the stigma associated with head surgery and potential mental impairment.

#16 Well, I don't have a job. I haven't been working since he got sick. I've been taking care of him the whole time. After the operation, because he is often ill from time to time, I always worry about it. I have been feeling nervous like this for several years now, from the early days when he was diagnosed to post-operation. As he has been constantly unwell, I don't care about anything else. Taking care of him is almost my whole life.

#13 How can I not be worried that my son isn't developing? If he could develop, I would have no trouble, but I feel like I can't live now. Professor Li said, if the treatment is timely, he may improve, otherwise I have two sons and face losing one, and in our village, this is especially difficult because of tremendous social pressure to have offspring.

Relieving the psychological pressure of minors

In terms of children, many caregivers (#04, #05, #09, #12, #18) reported that their adolescent patient was more irritable after surgery than before. Some caregivers described their sadness and confusion about this, and they thought what they felt was detrimental to maintaining a positive relationship. One minor patient (#04) expressed suicidal thoughts to the informal caregiver we examined, with the caregiver expressing helplessness at the time. Even with the aid of wigs, some caregivers (#03, #12, #15) did not know how to deal with

Table 2
Participant demographics.

No.	Primary caregivers							Children					Relationship of the two	Interview form
	Gender	Age (years)	Location	Education	Full-time Care	Length of care (Y:year; M: month)	Monthly Household Income (Yuan)	Gender	Age (years)	In Education	Relapse	Surgery Date*		
01	Male	38	Rural	High School or Below	No	>1Y; ≤3Y	≥5000;≤10,000	Girl	10	Yes	No	2020.10	Father-daughter	Online
02	Female	46	Rural	High School or Below	No	>1Y; ≤3Y	≥5000;≤10,000	Boy	13	Yes	No	2019.09	Mother-son	Online
03	Female	41	Urban	Master degree or above	Yes	≤6 M;>3 M	>10,000	Boy	5	No	No	2021.10	Mother-son	Offline
04	Female	50	Urban	College or Bachelor Degree	Yes	≤1Y; >6 M	>10,000	Boy	17	No	No	2021.04	Mother-son	Offline
05	Female	42	Rural	High School or Below	Yes	>1Y; ≤3Y	<5000	Girl	9	No	Unknown	2020.02	Mother-daughter	Online
06	Female	43	Urban	High School or Below	Yes	>1Y; ≤3Y	≥5000;≤10,000	Girl	18	No	No	2021.03	Mother-daughter	Online
07	Male	34	Rural	High School or Below	No	≤6 M;>3 M	≥5000;≤10,000	Girl	6	Yes	No	2021.12	Father-daughter	Online
08	Female	35	Rural	High School or Below	No	>3Y	<5000	Boy	12	No	Yes	2018.10	Mother-son	Online
09	Female	37	Rural	High School or Below	Yes	≤1Y; >6 M	<5000	Boy	10	Yes	No	2021.08	Mother-son	Online
10	Male	34	Rural	High School or Below	No	>1Y; ≤3Y	<5000	Boy	11	Yes	No	2020.12	Father-son	Online
11	Female	43	Urban	College or Bachelor Degree	No	≤1Y; >6 M	>10,000	Girl	12	Yes	No	2021.07	Mother-daughter	Offline
12	Male	43	Rural	High School or Below	No	>1Y; ≤3Y	≥5000;≤10,000	Girl	11	Yes	Yes	2019.05	Father-daughter	Online
13	Male	50	Rural	High School or Below	No	>1Y; ≤3Y	≥5000;≤10,000	Boy	17	Yes	No	2019.08	Father-son	Online
14	Male	36	Urban	High School or Below	No	>3Y	≥5000;≤10,000	Girl	15	No	Yes	2018.07	Father-daughter	Online
15	Female	33	Urban	High School or Below	Yes	<3 M	>10,000	Girl	15	Yes	No	2021.12	Mother-daughter	Online
16	Female	42	Urban	High School or Below	Yes	≤1Y; >6 M	>10,000	Boy	11	Yes	No	2020.05	Mother-son	Online
17	Male	32	Urban	High School or Below	No	>1Y; ≤3Y	≥5000;≤10,000	Boy	8	Yes	No	2020.12	Father-son	Online
18	Male	77	Rural	High School or Below	Yes	≤1Y; >6 M	<5000	Girl	16	No	No	2021.08	Grandfather-granddaughter	Online
19	Female	43	Urban	College or Bachelor Degree	Yes	<3 M	<5000	Girl	13	No	No	2021.03	Mother-daughter	Offline
20	Female	52	Rural	High School or Below	Yes	>1Y; ≤3Y	<5000	Boy	15	No	Yes	2019.06	Mother-son	Online
21	Male	42	Urban	High School or Below	No	≤1Y; >6 M	≥5000;≤10,000	Boy	11	Yes	No	2021.07	Father-son	Online

Table 3

Results.

Themes	Sub-themes	Codes
Needs for relieving psychological stress	Relieving the psychological pressure of minors	Reduce irritability Fear Alleviate the loneliness caused by relapse of illness The sense of shame Self-image disorder Psychological preparation for returning to work;
	Relieving the psychological pressure of caregivers	Relieve tension Eliminate stigma
Requirement for campus aid	Physical activity	Participate in appropriate physical activities Ensure safety in sports activities
	Eliminating verbal violence in schools	Verbal violence from classmates Inappropriate jokes from the teacher
	Special education needs for children	School for the blind School of art
	Health care services provided by school hospitals	To provide necessary endocrine monitoring needs; The university hospital provides medication administration needs; The school hospital supervises the physical activity needs of children
Demands for medical help	Acquiring medical knowledge	Complication management Basic medical knowledge Enrich the health management manual Develop electronic version of health management manual
	The need for medication management	Withdraw medication arbitrarily The desire for participating in dosage formulation Expanding the publicity of online treatment and consultation
	Convenience and reliable access to medical service	Improving community-level medical care Online medication delivery needs
	Needs for technological development	The need for monitoring urine volume expediently The development of early screening tools for craniopharyngioma
	Expectations of multidisciplinary cooperation	Promote cooperation between ophthalmology and neurosurgery Promote cooperation between endocrinology and neurosurgery Promotion of child Growth and Development department and neurosurgery collaboration
The desire for financial aid	The necessity of health review reminders	Urging magnetic resonance examination Urging endocrine review Call attention to BMI of children Call attention to the development of secondary sexual characteristics
	Charity platform assistance	Shuidichou(Fundraising platform)
	The inclination of government policy	Promoting the inclusion of outpatient expenses into medical insurance reimbursement Included in the entry of reimbursement for chronic diseases

short hair and scars following surgery. The imprint of the ventriculo-peritoneal drainage tube in the neck also upset children and their parents. These traces of illness act as a catalyst for low self-esteem and shame, which loom over children and caregivers (#12, #21) like an inescapable cloud. One of the appeals of informal caregivers is helping young patients out of psychological distress.

#21 He often asks, "Mom, why do I need surgery?" He also frequently asks me why he is different from everyone else. He feels like he is the only person in the world who gets sick all the time.

#04 He doesn't pay attention to learning anymore, he used to be very sweet and fond of learning, but he doesn't read books anymore. He gets angry easily, loses his temper, and says he wants to die (crying).

#12 She is just a little bit grumpier than before...she often asks if her scars are visible. Actually, her hair can cover her scars, but girls love to look pretty. She is worried about looking different. She had a ventriculo-peritoneal drain, and that drain tube shows marks in her neck when she is sitting. When I heard this, I told her not to tell anyone too much about her illness, and to say that it is just a blood vessel, but who would believe that lie?

Requirements for campus aid

Twelve of the young patients were still pursuing their education, whereas nine of them were not. Among caregivers of patients who

were not in school, most (7/9) expressed concerns about their children's healthcare, which was one of the factors that led to the children's suspension from school (#03, #05, #06, #08, #09, #12, #14, #15, #19, #20).

Physical activity

One of the frequent complications of craniopharyngioma surgery is visual impairment, which restricts children's participation in physical activities. Caregivers (#09, #15) of children still enrolled in education reported that the children did not participate in physical education. However, because obesity is another common postoperative complication, it was necessary for them to engage in exercise for weight control. They required specific advice from the physical education teacher at their school regarding the appropriate form and level of exercise.

#09 When he was discharged from the hospital, the doctor said he could take gym classes. The teacher of physical education believes that the child's physical condition is unsuitable for physical education, and that the school should be concerned about it in order to prevent accidental injuries. Since then, he hasn't taken PE classes anymore. We want our child to have suitable physical activity in school. After all, he tends to put on weight. The school hospital is not highly qualified. There's nothing we can do.

Healthcare services provided by school hospitals

For a long time, primary and secondary schools only had infirmaries, whose primary function is to provide very basic emergency care. There are three types of services that informal caregivers (#03, #06, #08, #14, #19, #20) expect school infirmaries to provide. Firstly, informal caregivers found it difficult for their children's 24-h urine output to be recorded at school, which was used as a reference during health reviews. According to their descriptions, they are willing to pay for health monitoring services provided by school infirmaries. The second kind of assistance they seek is medication management for school-age children. Due to intense academic pressure, children in China have to wait two or three weeks before they are permitted to take vacation in school. During school days, children were required to self-medicate, which is like a bomb attached to their body, with the potential to explode and injure themselves. Finally, physical education in schools should not be the responsibility of the physical education teachers alone. School hospitals should also provide guidance and monitoring of children's sports.

#06 Children only have one holiday following three weeks of schooling. During the three weeks of school, children are left to their own devices to take their medications, exercise, eat, and monitor their health. There are school doctors on-site, but they deal solely with emergencies and not special needs kids like her, which is why her father has consistently opposed allowing her to return to school.

Eliminating verbal violence in schools

A minority of caregivers (#12, #15) were of the opinion that it is inappropriate to make jokes about illnesses. Some unofficial caregivers (#09, #12, #15) expressed concern that children who experience verbal abuse at school may become depressed for a prolonged period of time. School teachers and students should show their concern for children after craniopharyngioma surgery rather than making inappropriate jokes on them.

#15 She suffered from low self-esteem as a result of some young boys in her class making inappropriate jokes and remarks about her scars and short hair. In actual fact, educators in schools need to be properly advised.

Special education needs for children

For a child with a severe visual impairment, one informal caregiver (#05) wanted the child to have the skill to earn a living when they became an adult. However, special education schools are mostly located in urban areas. Long distance is thus a worry for the child's family that lives in a rural area. The informal caregiver argued for the establishment of special schools in rural areas so that caregivers like her could conveniently care for kids following craniopharyngioma surgery.

#05 After the operation, she still has blurred vision. Her hobbies are tearing paper, folding paper, and drawing. When I asked her if she would like to go to a special school, she was very willing to go and was looking forward to the prospect. However, after I inquired, I discovered that such schools are only found in the larger cities. Because of where we live in the country and the fact that our child's body is unhealthy, we are concerned that she will be bullied if she moves anywhere else.

Demands for medical help

Four types of medical assistance are required. They are acquiring medical knowledge, having convenient and dependable access to medical care, need for technological advancement, and expectations of multidisciplinary collaboration (02, #04, #05, #06, #07, #08, #09, #10, #11, #17, #18).

Acquiring medical knowledge

Informal caregivers (#08, #10) who did not have friends or relatives working in the medical field and who did not possess medical

knowledge themselves found it extremely difficult to take care of the children after surgery. More than half of the respondents in this study came from a county or township with a low education level. They struggled to quickly pick up the medical knowledge they required, despite receiving health education at the time of discharge. Informal caregivers (#07, #10, #18) were less likely to accurately describe the condition of the child to doctors if they lacked basic medical knowledge. The needs of caregivers included the improvement of current health education manuals and the creation of electronic versions of health management manuals.

#07 I don't think my child feels cold now. Her hands and feet are red with cold, but she never says she feels cold. If you ask her if she is cold, she says no. (Question: Did you take her temperature? Is she hypothermic?) Yes, we measured her, but she didn't have a fever. She didn't have a high temperature. (Questions: Well, do you know what hypothermia is?) I don't know. No one ever told me that. But I always thought the point of taking your temperature was to see if you had a fever.

#08 We had the fourth operation performed in ** Hospital in Beijing. I think a benefit in comparison with this hospital is that for the postoperative recovery period, they provided some guiding pictures that can be seen on mobile phones. It would be nice if they could be more detailed.

Convenient and dependable access to medical care

Many children who had craniopharyngioma surgery were not vaccinated against COVID-19 due to their weakness. During the COVID-19 pandemic, the informal caregivers (#09, #18) had great concerns about hospital treatment and regional outbreaks across China. To the researchers' surprise, informal caregivers were unaware that hospitals were already offering online treatment and medication prescriptions in the early stages of the COVID-19 outbreak. During the regional lockdown, a few informal caregivers (#06, #07) also expressed a desire to receive treatment in primary hospitals if they could have faith in the quality of community-level healthcare.

#09 The prevention and control policy of the COVID-19 pandemic is strict again, and we are unwilling to travel far for our child to see a doctor. He is weak and we have not yet dared to vaccinate him. Could you help us communicate with the attending doctor to adjust the medicine? (QUESTION: Have you heard of online therapy?) No, we only know that we can make an appointment on the public WeChat account to see the results of the test, but no one ever mentioned online treatment.

#07 My child's illness is particularly complex, so I can't trust the medical services offered by county hospitals, but if the hospital had better medical conditions than it does right now, I would prefer to seek medical care locally.

Needs for technological development

Unhappy with the technology in place, one informal caregiver (#07) offered suggestions, such as whether children's illnesses might be less harmful if they were screened earlier. Another caregiver (#11) also wanted a device that can easily monitor a child's urine output at school, just as watches can monitor heart rate and breathing.

#07 If there is a community focused on this disease, I hope doctors focus on early screening research, so that families like ours can get the right advice and avoid wasting time. For about a year, she received ineffective treatment before an accurate diagnosis was made.

Expectations of multidisciplinary cooperation

After surgery, the requirement for caregivers (#10, #11, #17) to visit or alternate between several departments was a significant burden. Close coordination between various hospital departments is necessary to fully take into account complications, weight, height, and tumor recurrence management.

#10 His blood was taken at the endocrinology department of another hospital, and his hormone levels were checked. They claimed he had larger breasts, lower levels of testosterone and higher levels of

estrogen. Soon after, we checked to see if the tumor had recurred, and the surgeon said we needed a gamma knife. In the Growth and Development department, the doctor said the child needed a growth hormone injection. We are afraid for the child's growth, development, and tumor recurrence. The main reason is that his illness is extremely complex and requires careful consideration.

The necessity of health review reminders

Although the medical staff instructed the patient's caregivers to give regular reviews at the time of discharge, a few caregivers (#05, #18) claimed that their busy schedules made it difficult for them to keep track of the precise time of reviews. These rare phenomena might be related to the lack of knowledge of caregivers. This inferred the necessity for medical personnel to regularly remind unpaid caregivers to assist kids with health reviews in order to prevent irreparable harm to kids' growth and development.

#18 The child hasn't been reviewed yet. I was the only one left in the family to take care of her. Her uncle mainly paid for the medical treatment. I'm old and not well-educated, so I can't remember a lot of things. Sometimes she has to worry about what she's supposed to do. You mean she needs a review? What needs to be checked?

The need for medication management

On the one hand, informal caregiver (#02, #04) feedback revealed that there have been instances where younger children have stopped taking medication on their own. When the child was away from the caregiver's supervision, especially during the school day, medication compliance was poor. Informal caregivers wanted medical staff to teach children to take their medication on time, because they believe physicians have complete authority over the children regarding medication and treatment. However, given that hormonal medications directly affected private matters such as spermatorrhea, informal caregivers (#04, #18) reported that they and their adolescent patients wanted to be involved in dosage formulation.

#04 Now that the testosterone level in his blood is normal, I asked the doctor who said that he could reduce his dosage by one pill, as he said that my kid only needs to take one pill in the morning or in the evening. However, my son (#04) responded that he doesn't want to decrease his dosage or stop taking oral testosterone because he went a long time without experiencing spermatorrhea and is now experiencing it. He thought himself that he ought to continue the dose.

#02 He stopped taking the medication on his own initiative, which led to his hospitalization. When we asked him why, he responded that he didn't want to take it, didn't think he should take it, and didn't know much about it.

The desire for financial aid

The economic pressure of informal caregivers was immense. According to the description of informal caregivers (#09, #13, #14, #17, #19, #20), there were three compelling appeals, as listed below. First, post-operative children accepted health reviews mainly in the outpatient department. The cumulative cost of outpatient visits was significant for their families. They hoped that promoting the inclusion of outpatient expenses into medical insurance reimbursement could be implemented as soon as possible. Second, children who have had craniopharyngioma surgery must take medication for the rest of their lives. Some families could not afford expensive medicine, such as growth hormone. They hoped that the medical reimbursement of chronic diseases would cover these illnesses. Third, the recurrence of craniopharyngioma in children still requires multiple treatments. Caregivers hoped that the preferential medical insurance policy could be adjusted for such post-operative children. As described above, nearly half of the informal caregivers were full-time caregivers, and most of them were parents of minor patients, so the effect on family income was clear. In addition, with the occurrence of COVID-19 outbreaks on occasion, household

income, like that of the majority of typical families, has further decreased. As a result, some underprivileged informal caregivers submitted applications to the social charity platform, which was a clear indication of their need for financial assistance.

#14 She's undergone three surgeries so far. All costs, then, had to be borrowed for. Then I paid for the last surgery by crowdfunding on the ** platform. I can now say that I'm broke. Now, I'm working. I try my best to treat my child, just to be worthy of my heart.

#13 The cost of each treatment is around 5000 yuan, which is expensive for our family. Because my child needs to take medicine for life, I wanted to apply for chronic disease reimbursement. If this worked, it might be cheaper to get medicine at the hospital. However, following consultation, we have learned that this condition is not categorized as a chronic illness, so the expenses cannot be covered.

Discussion

This study aimed to identify the needs of informal caregivers of adolescents who have undergone craniopharyngioma surgery, and offer suggestions on how to best help them. The findings showed that their appeals were based on the need: for financial assistance, for campus assistance, for medical assistance, and to relieve psychological stress.

Similarities and differences

Findings of the present study have similarities and differences with previous research. In terms of similarities, the results of this study describe the need for participants to relieve their own psychological stress, including worries about returning to work, and the future of their children, consistent with the findings of Schubart et al. (2008). Moreover, in line with the findings of Nicklin et al. (2019), this study demonstrated the demand for medical assistance, including long-term follow-up, health management, and nearby medical care. Our research also revealed the requirements for campuses, as well as the concerns about the staff and doctors there, similar to the results of Paré-Blagoev et al. (2019).

Nevertheless, this study differs from the others in a number of ways. This study comprises Chinese participants, which might have made them reluctant to discuss their family disputes. Additionally, caregivers did not report a decline in support available when transitioning to adult services, which could be explained by the fact that the majority of the study participants were still children.

In conclusion, long-term care following craniopharyngioma surgery can present challenging obstacles for informal caregivers, and place them under great pressure. These recommendations for informal caregivers' requirements offer some specific pointers for addressing their care challenges.

Call for social collaboration

The health management of young patients who have undergone craniopharyngioma surgery requires both the multi-faceted cooperation of society, and the multi-disciplinary cooperation of medical institutions. According to the information provided by the informal caregivers, schools and health professionals should collaborate and help manage the health of young patients. Therefore, we recommend that medical professionals work together with the school infirmary to establish health records for those children, and assist in promoting on-campus hospital staff's as well as the physical education teachers' medical skills. We call on society to support children with special needs by using 5G signal transmission to establish communication platforms for schools, informal caregivers, and hospitals as required. Going back and forth between various departments after surgery is a significant burden for patients. Based on the existing experience of multidisciplinary cooperation, hospitals can establish cooperative programs for the neurosurgery, ophthalmology, endocrinology, and growth and development

departments. For these patients, doctors could create postoperative rehabilitation programs through multidisciplinary efforts. If necessary, they could also consult patients, schools, and informal caregivers to help create a reliable, long-term postoperative health monitoring system.

Improving the inconvenience caused by COVID-19

In light of the regional outbreaks of COVID-19 in China, it is necessary to strengthen the promotion of online medical treatment, provide adequate health education before patient discharge, and enhance medical care in community-level hospitals. The informal caregivers expressed serious concerns about hospital treatment during the outbreak; however, they were unaware that hospitals were offering online treatment and medication prescription in the early stages of COVID-19. Therefore, to alleviate the practical difficulties of informal caregivers, hospitals should increase the promotion of these treatment methods, and encourage patients and their families to use them, while demonstrations as necessary. Additionally, because of their limited education, informal caregivers reported having trouble understanding home care for complications. Therefore, hospitals should offer information in a variety of formats, such as oral explanations, videos, brochures and mobile phone software to ensure that informal caregivers thoroughly understand, and to improve their ability to provide care. Furthermore, patients who receive better primary care may trust county hospitals and be willing to receive care nearby. The risk of infection can be reduced in the event of a local COVID-19 outbreak by seeking treatment close to home.

Provide successive psychological support

It is the duty of medical professionals to provide psychological support and monitoring to informal caregivers and patients. It may be possible to help informal caregivers reduce their stress and enhance their quality of life by paying attention to their psychological needs and, if necessary, by offering proper psychological interventions. There is a mutual influence on the informal caregiver and juvenile patients' psychological state (Serçe & Günüşen, 2021). Helping informal caregivers relieve their stress may be helpful to children's well-being. Just as children need to return to school, informal caregivers must be mentally prepared to return to work. Helping families establish a relaxed atmosphere after surgery may help family members reestablish themselves socially. Additionally, there are many types of distress that should be paid particular attention, such as the emphasis girls place on their appearance; how the fear of a returning tumor can make one feel lonely; and how long-term medication and abnormal physical development can cause feelings of shame, leading to them even considering death. Thus it is necessary for the psychology department of the hospital to play an active role in the formulation of rehabilitation programs for children following craniopharyngioma surgery. The dynamic health monitoring system should include psychological evaluation and suicide warnings, which may be effective in preventing suicide.

Practice implications

This study summarized the needs of informal caregivers of children who underwent craniopharyngioma surgery. It is necessary for health care professionals to fully understand their requirements and provide effective help for them by optimizing service. The results of this research can also provide reference for policy makers and social workers to improve services.

Limitations and future research directions

This study has certain shortcomings. For example, a stratified analysis of children and adolescents was not carried out; further analysis of

the needs of children and adolescents could shape the development of future health management projects. Additionally, we did not speak with the young patients directly. There is a dynamic interaction between young patients and their primary caregivers, and the parent-child relationship may play a role in the outcome of health management. Understanding the needs of minors may help medical professionals provide effective support. Furthermore, the researchers' knowledge is limited, so we may be unable to ascertain further information to support the findings. Finally, we were unable to design an entry in the interview outline for differences in demand before and after the COVID-19 pandemic.

The following points need to be taken into consideration in future research and practice. The development of a 5G dynamic health monitoring system, portable urine volume detection equipment, and technology to remind patients of health reviews should be encouraged in the first place as these would be helpful for the management of the minor patients' health. Secondly, the development of early screening tools for craniopharyngioma is considered to be vital by some informal caregivers, who believe that early detection and surgery may lead to less of a negative impact on their health, since the diagnosis of childhood craniopharyngioma is often late, frequently years after the manifestation of initial symptoms (Müller et al., 2019). Thirdly, the promotion of multidisciplinary cooperation is key to improvement of hospital care. Furthermore, advocating the reimbursement of chronic disease-related costs to the policy makers is also worthwhile, because postoperative care of craniopharyngioma necessitates long-term medication. Last but not the least, promoting links between top-level hospitals and community hospitals will assist patients in finding the right care quickly and effectively in the face of COVID-19.

Conclusion

Caregivers need the multi-disciplinary cooperation of medical institutions (psychology department, neurosurgery, ophthalmology, endocrinology, growth and development department, etc.) to provide professional advice for the health management of children. They also require the multi-faceted cooperation of society (school, medical institutions, government, social charities, etc.) to provide technical support for monitoring the health of minor patients. In the context of COVID-19, it is necessary to enhance medical care of community-level hospitals, and promote the practical application of online medical treatment and prescriptions.

CRedit authorship contribution statement

Kun Du: Conceptualization, Methodology, Writing – original draft, Writing – review & editing, Formal analysis, Funding acquisition. **Yuan Yuan Pan:** Formal analysis, Validation, Supervision, Funding acquisition. **Wen Wen Yan:** Formal analysis.

Declaration of Competing Interest

We declare that we have no financial and personal relationships with other people or organizations that can inappropriately influence our work in the manuscript entitled "Qualitative Descriptive Study during the COVID-19 Pandemic on the Needs of Informal Caregivers of Chinese Minors who underwent Craniopharyngioma Surgery".

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Appendix A

Framework	Question Examples
Physiology and Safety	<ol style="list-style-type: none"> 1. After the operation, how do you think the child's physical condition, healthy, sub-health or disease? 2. What complications occurred after the (first) craniopharyngioma surgery? 3. Is the child still on medication? (If the answer is Yes)What impressive things have happened with home medication? (If the answer is No)What happened that caused your child to stop taking medication? 4. What worries you most about your child's health or your health? How did you deal with it?
Psychology	<ol style="list-style-type: none"> 1. How is the relationship now between you and the patient? (If the answer is Good)What does your child talk to you most or what words impressed you most in the psychic conversation? (If the answer is Bad)What happened to your relationship with your children? 2. How has your mood changed since the surgery?(If the answer is not good)What do you do when you feel down?
Society	<ol style="list-style-type: none"> 1. What do you think of social help for a family situation like yours? What kind of help is effective for a family situation like yours? 2. (If the child is not in education)Why did your child drop out of school? 3. (If the child is in education)What do you think of your child's relationship with his siblings, friends or classmates? How did he/she describe it to you?
Others	<ol style="list-style-type: none"> 1. What efforts have you made to manage your children's health? 2. What advice would you give to the primary caregiver about health management for a family in the similar situation? 3. What is the most difficult thing after the Craniopharyngioma surgery? 4. How did your child's operation affect you?

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