Qualitative Study on the Care Experience and Needs of Primary Caregivers for Children Undergoing Hypospadias Surgery

Can Zheng[1], Xia Zhou[2,*], Huajuan Du[1], Liping Cheng[1]

[1] Dali University, Dali, Yunnan, China

[2] Kunming Children's Hospital, Kunming, Yunnan, China

[*] Corresponding author: gandanyipi@sina.com

Abstract: Objective: To explore the experiences and needs of primary caregivers of children undergoing hypospadias surgery during the care process, and to provide a basis for optimizing family care strategies and nursing interventions. Method: Using purposive sampling method, 13 primary caregivers were selected for semi-structured interviews in December 2024, and Colaizzi 7-step analysis method was used to summarize and extract themes. Result: extract four themes, including the dual experience of psychological conflict and emotional adjustment, the caregiving dilemma under multidimensional knowledge and skill gaps, the heavy burden of family caregiving, and the desire for sustained and diverse professional support. Conclusion: Caregivers generally face significant psychological pressure and caregiving difficulties, and expect systematic, flexible, and sustainable nursing guidance and social support. Medical staff should pay attention to their emotions and needs, establish a care support system that runs from preoperative to home care, strengthen personalized health education, continuity of services, and integration of diverse social resources, enhance their caregiving abilities, and promote postoperative recovery of pediatric patients.

***Keywords*:** hypospadias; caregivers; care experience; nursing needs; qualitative research

1. Introduction

Hypospadias is one of the most common congenital developmental abnormalities of the urogenital system in children, characterized by abnormal urethral opening, and some children are unable to urinate while standing[1], Severe cases may also affect sexual function [2] and fertility in adulthood [3,4]. The global incidence rate of the disease is about 1.86/1000, and that of China is about 1/300-1/200 [5], showing an upward trend year by year [6, 7]. At present, surgical correction is the only effective way to treat hypospadias [8], but the incidence of postoperative complications is as high as 10.7% to 53.8% [9], and the reoperation rate is as high as 39.2% [10]. Due to the fact that many children undergo surgery during infancy and early childhood, their compliance is poor, and postoperative care mainly relies on family caregivers. If caregivers lack relevant disease awareness and nursing skills, it may be difficult to detect and treat postoperative complications in a timely manner, thereby affecting the recovery process of the children [11]. In addition, postoperative nursing tasks are heavy and the care cycle is long, which also puts significant psychological pressure and caregiving burden on caregivers [12]. Although previous studies have explored the basic needs or psychological burden of parents of children with hypospadias in postoperative home care through questionnaire surveys or qualitative methods [13-15], most of them focus on quantitative surveys of nursing knowledge or health education content, lacking a deep understanding of psychological experiences, care barriers, and support expectations in the actual care process. At the same time, they mostly focus on negative emotions and pay less attention to the positive coping and positive experiences of caregivers. Therefore, this study uses phenomenological methods to conduct in-depth interviews with caregivers, aiming to comprehensively reveal their emotional reactions and health needs during the caregiving process, make up for the shortcomings of current research, and provide a basis for constructing more targeted continuity of care and family support strategies.

2. Object and Methods

2.1 Object

Using purposive sampling method, the main caregivers of children with hypospadias admitted to the urology department of a tertiary hospital in Yunnan Province in December 2024 were selected as the research subjects. Inclusion criteria: ① being the primary caregiver for the child, with a daily care time of ≥ 4 hours and a weekly care time of ≥ 5 days [16]; ② Age ≥ 18 years old; ③ Physically and mentally healthy, with normal communication skills; ④ Informed consent and voluntary participation in this study. Exclusion criteria: ① Children with genetic diseases or other serious comorbidities (such as

severe cardiovascular, liver, and kidney dysfunction); ② The primary caregiver who needs to pay; ③ Recently (within 3 months) experienced significant stress events (such as bereavement or divorce); ④ I am currently involved in other research. This study was approved by the Ethics Committee of our institution (2024-03-272-K01). The determination of sample size is based on the principle of achieving theoretical saturation of interview information (i.e. no new topics appearing). Finally, by the time of interviewing the 13th research subject, the information had reached saturation, so a total of 13 primary caregivers were included in the study. General information is shown in Table 1.

Table 1. General information of primary caregivers (n=13)

Number	Gender	Age (years)	Marriage Situation	Relationship with the patient	Educational Level	Household monthly income (yuan)	Occupation	Shared photo Number of people
N1	man	43	married	father	junior high school and below	<3000	farmer	2
N2	woman	32	married	mother	junior high school and below	<3000	farmer	1
N3	woman	36	married	mother	high school	3000-5000	Unemployed or unemployed	2
N4	woman	31	married	mother	junior high school and below	3000-5000	Unemployed or unemployed	1
N5	woman	34	married	mother	college degree or above	3000-5000	worker	1
N6	woman	31	married	mother	high school	3000-5000	farmer	1
N7	man	34	married	father	college degree or above	5000-8000	Civil servants/ public institutions	2
N8	woman	36	married	mother	high school	3000-5000	worker	2
N9	woman	29	married	mother	college degree or above	≥8000	worker	1
N10	man	37	married	father	high school	3000-5000	farmer	2
N11	woman	37	married	mother	college degree or above	≥8000	Civil servants/ public institutions	2
N12	man	35	married	father	junior high school and below	<3000	farmer	1
N13	man	32	married	father	college degree or above	≥8000	Civil servants/ public institutions	2

2.2 Methods

2.2.1 Determine Interview Outline

Based on the research objectives, literature review was conducted and a preliminary interview outline was formed through discussion by the research team. After consulting with 3 urological medical experts and 4 nursing experts for revision, and conducting pre interviews with 2 primary caregivers, further adjustments were made to form the final interview outline as follows: ① What unforgettable experiences and experiences have you had while taking care of your child? ② What is the biggest concern you have during your child's treatment process? ③ What knowledge do you want to learn during the treatment of your child's illness? ④ What aspects of health education do you think family caregivers should focus on during the treatment of children? ⑤ What kind of help and guidance do you hope to receive from doctors, nurses, or other medical professionals? How would you like to obtain this help and guidance?

2.2.2 Data Collection

Before the formal interview, the researcher explains key information such as the purpose, content, and methods of the interview to the interviewee, and signs an informed consent form. Both parties agreed to conduct interviews in a quiet and comfortable location during the treatment interval, with each session lasting approximately 30 minutes. During the interview, the researcher asked flexible and neutral questions based on the outline, ensuring that the answers were objective and truthful, and recorded the entire process. After the interview, all information shall be strictly kept confidential and properly preserved.

2.2.3 Data organization and analysis

Within 24 hours after the interview, the researcher transcribed the recorded data word for word into text and anonymized the text data. This study used the Colaizzi seven step analysis method [17] to systematically analyze interview data, and all data were managed, coded, and topic extracted using NVivo 12.0 software.

2.2.4 Quality Control

Before the official start of the interview, all members of the interview team systematically studied the relevant theories of qualitative research and mastered the methods of data analysis and processing. During the interview process, the researcher flexibly adjusted the interview sequence and communication methods based on the interviewee's actual situation, taking into account the interview outline. Throughout the process, the researcher remained objective and neutral, without making any form of suggestion or guidance, and actively clarified vague or ambiguous statements. In addition, considering the potential differences in care needs caused by factors such as the age of the affected children and the educational level of the primary caregivers, this study selected interviewees based on the principle of maximum differentiation.

3. Results

3.1 Theme 1: Dual Experience of Psychological Conflict and Emotional Adjustment

3.1.1 Concerns and Anxiety

The primary caregivers generally face enormous psychological pressure, especially in terms of surgery, safety, recovery, and future fertility, showing strong concerns. These anxious emotions not only affect the caregiver's own mental health, but may also affect the quality of postoperative care and recovery process of the child. N2: Can half anesthesia be used for surgery? I am concerned that general anesthesia may have an impact on the child's future development, and I am also worried that the surgery may not be performed properly, which could affect future fertility and sexual life. N4: "I am very worried about postoperative infections and secondary surgeries. Watching the child suffer, I feel uncomfortable." N5: "I am very concerned that this disease will have long-term effects on the child's physical and mental health, especially the potential psychological burden it may bring.

3.1.2 Self blame and guilt

Some primary caregivers may attribute the cause of their child's illness to themselves, suspecting whether it is due to their genetic makeup or certain behaviors during pregnancy (such as drug use, lifestyle habits, etc.) that led to the child's illness. This uncertainty and fear of the unknown translate into a deep sense of self blame. N3: "When my child was first born, I felt very angry and sad. I don't know why he got this disease. Then when the child was on the operating table, I couldn't help but cry. Seeing him go on the operating table at such a young age, I felt very sorry, "N6 said." I'm not sure if the child's illness is related to intrauterine growth disorder or some of my behavioral habits during pregnancy. When I think about these, I feel very guilty.

3.1.3 Optimism and Hope

Despite facing pressure, many caregivers still strive to maintain an optimistic attitude and have confidence in the medical team and rehabilitation outcomes. They enhance their sense of hope through seeking information, social comparison, and other means, and this positive emotion plays a positive psychological regulatory role in the caregiving process. N7: "At first, I thought this disease was rare, but when I was admitted to the hospital, I found that many children had this disease, and their ages were also different. Some children recovered well after surgery, and I felt a little better." N13: "Before choosing your hospital for surgery, I consulted some parents who had undergone surgery in your department, and they were all satisfied with the surgical results and the recovery of their children, which made me feel a lot more at ease.

3.2 Theme 2: Care dilemma under multidimensional knowledge and skill gaps

3.2.1 Insufficient understanding of disease-related knowledge

Most caregivers stated that they had never heard of the disease "hypospadias" before the child was diagnosed, and their knowledge mainly relied on online searches. However, the complex and difficult to distinguish true and false content of online information not only fails to meet their needs for specialized knowledge of diseases, but also increases their anxiety and uncertainty. N3: "After learning that my child was sick, I searched for some information online, but I am not sure about the accuracy of the information and I am not very clear about the treatment methods. N10: "I can't find the incidence rate and classification information of this disease on the Internet. I really want to know what type my child belongs to.".

In addition to a vague understanding of the basic concepts of the disease, most caregivers also lack a systematic understanding of the possible complications that may occur after surgery, making it difficult to identify abnormal signs and unclear about corresponding coping measures. This knowledge gap has to some extent weakened their confidence in caregiving and increased the possibility of postoperative risks not being addressed in a timely manner. N3: "I want to know what complications may occur after surgery, and what consequences these complications may bring." N9: "I don't know much about postoperative complications, only urinary fistula and stenosis, mainly found them online. I hope you can provide a detailed explanation of any other complications, their specific manifestations, and how I should respond.

3.2.2 Weak perioperative family care skills

3.2.2.1 Confusion in Dietary Management

A reasonable diet after surgery is an important guarantee for promoting tissue healing and reducing complications. However, most caregivers lack specific understanding of dietary arrangements, especially when it comes to "taboo" foods, and are concerned that improper diet may affect wound recovery. N4: "How should a child's postoperative diet be arranged? Is there anything special to pay attention to? What foods should be avoided? "N13:" I think diet is very important. I am worried that my child's consumption of the traditional Chinese medicine term 'organic compounds' may affect wound recovery, but you have not provided specific dietary guidance on how to eat them. This is crucial.

3.2.2.2 Concerns about Improper Wound Care

Postoperative wound care is an important link in ensuring surgical outcomes and promoting recovery. However, caregivers generally report a lack of knowledge in wound management and are concerned about adverse consequences such as wound infection and rupture due to improper care, especially when it comes to the child's sleeping position and turning over at night. N5: "The child is very active. What if they bump into the wound? Does a child's tendency to sleep on their stomach at night affect wound recovery. N10: "I am very concerned about wound infection and what symptoms may occur after infection.

3.2.2.3 Fuzzy activity management

The arrangement of postoperative activities is crucial for wound protection and functional recovery, but caregivers generally lack a clear understanding of key time nodes such as the time for the child to get out of bed, exercise control, and return to school. N6: "What are the precautions for children's postoperative activities? How long after surgery can I get out of bed and move around? "N9:" How long after discharge can I not engage in vigorous exercise, and when can I go to school normally.

3.2.2.4 High pressure of catheter care

Postoperative indwelling catheter is a routine measure after urethroplasty, but the maintenance of the catheter poses a high operational difficulty for non professional caregivers. Most caregivers express that they do not have experience in this area and are concerned that inadequate care may cause infection or blockage, therefore they crave for intuitive and practical operational guidance. N4: "I don't know how to take care of my child's urinary catheter. Can you record a nursing video? We are particularly afraid of infection caused by poor care ", N12:" We need to bring a urinary catheter home, but we don't know how to take care of it. We are both afraid of the tube clogging and worried about infection.

3.2.3 Insufficient communication skills between parents and children and society

Caregivers not only need to deal with medical care issues for sick children, but also face communication challenges within society and families. Some caregivers expressed that the abnormal urination mode of the child can easily arouse curiosity and misunderstanding from others, making them feel embarrassed. As the child grows older and their self-awareness increases, they begin to perceive differences and actively ask questions. Caregivers often feel a lack of language when facing children's questions and external doubts, making it difficult to strike a balance between protecting the child's self-esteem and explaining the nature of the illness. N2: "People in the village often ask why the child is squatting to urinate. Now that the child is older, they also ask me why I am different from other children. I don't know how to answer or explain this disease to the villagers." N5: "When the child grows up, I don't know how to communicate with him or explain this disease to him.

3.3 Theme 3: Facing the Heavy Burden of Family Care

3.3.1 Increased economic pressure on families

Due to the complex condition of some children, they need to undergo multiple surgical treatments, resulting in a significant increase in family medical expenses. For some families with limited economic conditions, the continuous cost of treatment and rehabilitation constitutes a heavy burden. N2: "My child may need to undergo two surgeries, which is too

expensive. We are all from rural families, and the economic pressure feels quite high." N12:.

3.3.2 Interweaving of caregiving pressure and psychological burden

Due to the long recovery time and high risk of complications after surgery, family caregivers not only have to bear heavy caregiving tasks, but also face enormous psychological pressure. They may experience anxiety due to concerns about the recovery status and prognosis quality of the sick child, as well as increased psychological burden caused by care conflicts and social attention pressure from multiple sick children. N8: "I also often worry about my child's future, afraid that this disease will affect his growth and mental health. Besides, taking care of him is also very troublesome, and we don't know how to take good care of him, which puts a lot of pressure on our hearts. "N12:" The child is very mischievous, and we have two other children at home. I'm worried that the urinary catheter might be pulled. When taking children out, they are also afraid that others will laugh at them when they see the urinary catheter, which puts a heavy psychological burden on them.

4. Discussion

4.1 Pay attention to the emotional reactions of caregivers and provide multi-level psychological support

This study found that most caregivers of children with hypospadias have prominent mental health problems during the diagnosis and treatment process, manifested as deep concerns about surgical safety, postoperative recovery, future fertility, and other aspects, accompanied by varying degrees of anxiety, self blame, and guilt, consistent with the research of Wei Jiali et al[18]. Their negative emotions are often associated with long disease recovery cycles, multiple surgeries, high risk of complications, and heavy caregiving tasks [19, 20]. It is worth noting that some caregivers exhibit positive coping strategies such as actively seeking information, building trust, and emotional self-regulation in high-pressure situations, demonstrating a certain level of psychological adjustment ability. This positive psychological adjustment dimension, which has received less attention in existing literature, is an important supplement and extension to this study. From the perspective of psychological mechanisms, if caregivers have strong cognitive adjustment abilities and positive psychological states, they are more likely to drive children to form positive coping attitudes, thereby improving their overall treatment experience [21]. Therefore, clinical nursing staff should consider emotional support as an important aspect of caregiver management: on the one hand, it helps them to have a correct understanding of the disease and treatment process, reducing anxiety caused by uncertainty; On the other hand, non pharmacological interventions such as music therapy, mindfulness therapy, and "wheezing" care can be incorporated into postoperative care to enhance their psychological resilience [22, 23].

4.2 Strengthen care guidance and build a support system that runs through the entire process

This study found that caregivers have significant deficiencies in disease awareness, nursing skills, and ongoing guidance, which seriously affect their nursing confidence and practical ability. This phenomenon is consistent with existing research [24-26]. Failure to fully understand the causes and procedures before surgery, and difficulty in mastering key skills such as catheter management, wound care, and constipation management after surgery, make them feel helpless and panicked when facing home care tasks. Although some caregivers have received preoperative health education, it is difficult to translate the information into practical abilities due to its complexity, single form, and generalized content. In addition, traditional educational methods often lack personalization and sustainability, making it difficult to meet the needs of complex caregiving situations. This study further found that caregivers generally expect to receive flexible and continuous nursing support through WeChat groups, video teaching, online Q&A, and other means. Therefore, a full cycle and multi form care education system should be established: preoperative attention should be paid to the differences in caregivers' cultural level and understanding ability, providing a combination of text and images, gradual and phased education [13]; Strengthen postoperative training on key care skills, using bedside demonstrations, video teaching, PPT presentations, and other methods to enhance practical confidence; After discharge, continuous nursing models such as online teaching and Q&A groups are used to provide guidance, thereby improving the quality of family care and caregiver confidence.

4.3 Multidimensional integration of social resources to alleviate long-term care pressure

This study shows that caregivers face multiple challenges such as heavy caregiving tasks, economic burdens, and psychological pressure, which is consistent with the research results of Yu Yunfei et al[27]. The caregiving burden is closely related to the family's economic status, number of surgeries, caregiving cycle, and lack of social support, and the caregiving burden is dynamically changing, which is not conducive to the physical and mental health of caregivers and the recovery of children. Especially in rural areas or families with multiple children, caregivers lack alternative care resources and do not receive sufficient emotional support and economic assistance, leading to long-term high-pressure situations. Although some

caregivers have basic caregiving abilities, they are prone to fatigue and isolation due to insufficient social understanding, life pressure, and physical and mental exhaustion, which increases the risk of recovery for the affected children. Suggestions for promoting the construction of a social support system from three aspects: firstly, providing economic assistance, establishing medical subsidies or special funds for children with special diseases such as hypospadias, and reducing the economic pressure on families; Secondly, medical institutions can provide psychological counseling to help caregivers cope with negative emotions and enhance their psychological resilience; Thirdly, improve the care guidance and companionship mechanism, promote the popularization of family care knowledge and remote services. By integrating medical, policy, and social resources, the structural care burden on caregivers can be more comprehensively alleviated, and the long-term rehabilitation environment for children can be optimized.

5. Conclusion

This study explored the care experience and support needs of primary caregivers for children with hypospadias after surgery through qualitative interviews. The results showed that caregivers generally face dual challenges of psychological conflict and emotional adjustment, lack disease knowledge and nursing skills, and insufficient continuity of nursing support after discharge; Simultaneously bearing long-term economic, living, and social pressures, the caregiving burden is significant. They expect to receive continuous and flexible professional guidance and emotional support. It is recommended to establish a personalized support system throughout the entire process through psychological intervention, care education, continuity services, and social support in clinical practice, optimize family care, and promote the recovery of pediatric patients. As this study is a single center research, the results may be influenced by regional and cultural differences. In the future, multi center and mixed methods research can be conducted to deepen the understanding of caregiver needs and construct intervention pathways.

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